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SEEKING TO UNDERSTAND TELEPHONE SUPPORT
FOR DEMENTIA CAREGIVERS:
A QUALITATIVE CASE STUDY

By

JENN SALFI, R.N., Ph.D. (c)

A Sandwich Thesis

Submitted to the School of Graduate Studies

In Partial Fulfillment of the Requirements

For the Degree Doctor of Philosophy

McMaster University

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SEEKING TO UNDERSTAND TELEPHONE SUPPORT

DOCTOR OF PHILOSOPHY (2004)
(Health Sciences)

McMaster University
Hamilton, Ontario

TITLE:

Seeking to Understand Telephone Support
For Dementia Caregivers:
A Qualitative Case Study

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NUMBER OF PAGES:

xvi, 152

ABSTRACT

Telephone support is an intervention that is capable of delivering information, education, and psychosocial support to informal caregivers of persons with dementia. However, there has been very little research published examining the intervention of telephone support and its effect on the caregiving experience. A critical review of the literature revealed little information about the dimensions of telephone support and the experiences of those who receive and provide this intervention. Qualitative research is needed to achieve an enhanced understanding of telephone support services, and to understand the perspectives of those involved in this service.

This thesis describes a qualitative case study seeking to understand the intervention of telephone support for caregivers of persons with dementia. In-depth interviews were conducted with eight dementia caregivers and four telephone support providers. The dimensions of telephone support identified were information, referral, emotional support, and convenience. The experiences of caregivers with this intervention revealed the sense of companionship offered through telephone support. The experiences of the providers revealed telephone support as a means to assist and empower caregivers to meet their needs for information, referral, and emotional support. The professionals also described some of the frustrations experienced when providing this form of support.

After interpreting the data on the dimensions of the caregiving experience and the intervention of telephone support, it was evident how such an intervention can impact the

dementia caregiving experience. Not only does telephone support conveniently meet the needs of caregivers, but it helps to minimize negative outcomes such as loneliness and role isolation, and helps foster positive outcomes such as mastery and self esteem. This new knowledge has implications for the planning and delivery of telephone support that will meet the individualized needs of caregivers of persons with dementia.

ACKNOWLEDGEMENTS

Successful completion of this dissertation has only been made possible because of the several individuals who have provided guidance and support throughout this experience. I extend my heartfelt appreciation to my thesis committee at McMaster University for their continuous efforts and encouragement throughout my graduate career and through this research process. A special thank you to Dr. Jenny Ploeg, who has provided not only boundless support and expertise over the past five years, but who has been an inspiration and exceptional role model as a faculty member and as a scientist in the field of community health. I am also fortunate to have been mentored by Dr. Margaret Black and Dr. Sheryl Boblin. I am grateful for their commitment, insight, editorial, and emotional support throughout this final component of my doctoral studies.

I am grateful for the personal and financial assistance provided by Gertrude Cetinski and Sheree Meredith from the Alzheimer Society of Hamilton and Halton, and from Dale Marshall from the Victorian Order of Nurses (VON) Caregiver Support Program in Hamilton, Ontario. I am both indebted and honoured to have met all of the caregivers and telephone support providers who were willing to take the time and share their experiences with me. I admire your actions, and hope that this dissertation will in some way assist you in your endeavours.

I am also thankful for the on-going support from the Wellington-Dufferin

Community Care Access Centre (CCAC) and the Registered Nurses Association of Ontario (RNAO). Your financial contributions throughout the past three years have been greatly appreciated and shall never be forgotten.

Most importantly, I'd like to extend a very special thank you to my future husband Corey, my parents Betty and Frank, and siblings Joe, Ali and Megan. Each one of you has contributed something very special throughout this experience that has allowed me to remain focused and driven to complete this degree. Your everlasting faith and encouragement has inspired me to accomplish any goal I set for myself, and I could not have fulfilled this dream without you. Thank you, and I love you all.

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LIST OF ABBREVIATIONS

BI:	Burden Interview (Zarit & Zarit, 1990)
CCAC:	Community Care Access Centre
CCTR:	Cochrane Controlled Trials Register
CDSR:	Cochrane Databases of Systematic Reviews
DARE:	Databases of Abstracts of Reviews of Effectiveness
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
MeSH	Medical Subject Headings
RCT	Randomized Control Trials
REACH	Resources for Enhancing Alzheimer Caregiver Health
REB	Research Ethics Board
RNAO	Registered Nurses Association of Ontario
VON	Victorian Order of Nurses

CHAPTER ONE

Introduction

The inspiration for this dissertation came from both personal and professional experiences. With past professional experiences as a visiting nurse and present experiences as a community case manager at an Ontario Community Care Access Centre (CCAC), I have had the honour of working with a variety of individuals and their informal caregivers (family members who have assumed responsibility for caring). As a case manager responsible for managing both human and financial resources at the CCAC, I have observed first hand the struggles of informal caregivers, in part due to the reduction of home care services and shortage of home care workers. On a personal level, I continue to witness and learn about the consequences of caregiving as I observe a close family member provide care for a spouse suffering with dementia.

A considerable proportion of people aged 65 and older are providing care to their spouses, friends and neighbours (Cranswick, 1997). Every caregiving experience is different, and reasons for selecting both formal and informal supports vary based on how family caregivers perceive their experience. As researchers are beginning to acknowledge the importance of recognizing both the negative and positive effects associated with each caregiving experience, emphasis is now being placed on the development and maintenance of interventions and programs that both support the positive effects and minimize the negative consequences of caregiving. To date, interventions focused solely on minimizing the negative consequences of caregiving, for

example relieving burden, have not demonstrated effectiveness in meeting the needs of caregivers of person with dementia (Acton & Kang, 2001; Schulz et al., 2002).

Telephone support, through the delivery of information and psychosocial support, has the potential to both enhance the positive effects, and minimize the negative impacts associated with the caregiving experience. However, there are few published research studies that examine the effectiveness of telephone support as an intervention for caregivers. Furthermore, there are few studies that describe the experiences of informal caregivers with telephone support, and there is an absence of research investigating the experiences and perspectives of providers of telephone support. Both of these perspectives are crucial for understanding how telephone support services could be improved to assist informal caregivers at home, and for the planning and delivery of such services.

Organization of Dissertation

This dissertation is a “sandwich thesis”, a compilation of three articles that will be submitted for publication in scholarly journals after the thesis defence. To assist with the flow of the thesis, abstracts for each article have been withheld at this time, and will be added when the papers are submitted for publication. All work contained within this thesis has been undertaken as part of the PhD research work, and none of the papers (Chapters 2, 3, 4) have been submitted for previous graduate courses or comprehensive exams.

This thesis has been formatted to include the essential components of a standard graduate level dissertation. The second, third and fourth chapters of the thesis are extended versions of articles intended for publication. Consequently, there will be slight overlap between the chapters. The second chapter is a review and critical appraisal of the existing literature on telephone support for caregivers. The third chapter describes the methods of data collection and analysis involved in the study, and the challenges encountered while conducting qualitative inquiry with caregivers. The fourth chapter summarizes the findings of the study, including the perspectives of both caregivers and providers related to telephone support. Chapter Five concludes with implications for future research with dementia caregivers, and implications for practice. All appendices are included at the end of the thesis.

The purpose of this introductory chapter is to provide background information on caregiving, including both the negative and positive effects of caregiving. This chapter will also introduce the intervention of telephone support, and outline the purpose and research questions of this study. The references cited in this introductory chapter are listed on pages 120-122.

Background

Informal Care in the Home

In the last decade, there has been a major shift in care to the community as a result of the recent restructuring of the health-care and social service systems. Canada's growing elderly population, budget constraints and technological advances have led to reduced inpatient hospital stays, a shortage of available nursing home beds, and an

emphasis on post-acute services in home care (Merlis, 2000). This shift in care to the community has contributed to an increased level of responsibility placed on informal support networks of family and friends (Grunfeld, Glossop, McDowell, & Danbrook, 1997).

Informal caregivers are largely responsible for providing care to community-dwelling older persons who suffer from chronic physical or mental illnesses. According to the 1996 General Social Survey, more than two million people in Canada provide an average of four to five hours of informal care per week (Cranswick, 1997). Most of these caregivers are middle-aged women. It is expected that the number of informal, community-based caregivers will increase dramatically as a result of the world's aging population (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002).

Negative and Positive Effects of Caregiving

Caregiving can be conceptualized as a complex process characterized by both negative and positive dimensions (Kane & Kane, 2000). The 1996 General Social Survey reported that 45% of Canadian informal caregivers had modified their social life, 44% had incurred financial costs, 29% reported changes in their sleep patterns, and 21% reported that their health had been affected as the result of their caregiving duties (Cranswick, 1997). Caregiver burden, a commonly recognized negative consequence of caregiving, is defined as the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired adults (George & Gwyther, 1986). Because of the physical, psychosocial and financial burden associated

with caregiving, providing support to informal caregivers has become an increasingly important research and policy issue.

Recent research demonstrates that levels of caregiver burden can be reduced, by fostering positive aspects associated with caregiving (Greenberger & Litwin, 2003). Positive outcomes of caregiving have been identified as originating from within the caregiver through self-fulfillment and meaning, and/or from the care recipient, through reciprocal exchanges of support and affection (Kramer, 1997). Telephone support is one intervention that has the potential to facilitate management of caregiver burden by fostering positive effects such as caregiver empowerment and self-fulfillment.

Support Needs of Caregivers and Preference for Telephone Support

The needs of informal caregivers vary with their stage of life, the acuity and intensity of the caregiving situation, and the length of time as a primary caregiver. Researchers have identified the needs of family caregivers as information and psychosocial support, respite services and financial compensation (Cranswick, 1997; Ploeg, Biehler, Willison, Hutchison, & Blythe, 2001).

Three recent studies have addressed the support needs of informal caregivers and identified their preference for telephone support (Colantonio, Cohen, & Corlett, 1998; Colantonio, Kositsky, Cohen & Vernich, 2001; Ploeg et al., 2001). In a study by Colantonio et al., (1998), data from 84 telephone interviews with informal caregivers of persons with dementia aged 60 years of age and older revealed that only 8% of

caregivers were already using telephone support services, while 57% of non-users wanted to use this service.

In a second study, the Canadian Study of Health and Aging Caregiver questionnaire (Colantonio et al., 2001) was used to assess interest in support strategies among caregivers of elderly persons. The sample was comprised of 188 senior-caregiver dyads of which 45% expressed interest in telephone support services from a professional, and 41% expressed interest in receiving telephone support from a fellow caregiver. The authors strongly suggested that telephone support be added to existing caregiver support services.

In the most recent study, perceived support needs of family caregivers of persons living with chronic illness (physical or cognitive) were identified, and the characteristics of telephone support services preferred by caregivers were described (Ploeg et al., 2001). In this qualitative research study, most of the 34 caregivers interviewed stated that they would use a telephone support service provided by a professional (71%) or a fellow caregiver (59%) if available.

Telephone support is one method of delivering information, education and psychosocial support to informal caregivers, and has been proposed as a cost-effective alternative means of delivering selected home-care services (Short & Saindon, 1998). Advantages of telephone support over other types of support (ie. support groups, respite, education sessions) include delivery at convenient times, with privacy, and tailoring to the needs of the individual caregiver who may be housebound with very little time in their day in which to seek and receive support (Goodman & Pynoos, 1990).

All three studies of support preferences of caregivers (Colantonio et al., 1998; Colantonio et al., 2001; Ploeg et al., 2001) identified the need for further research and evaluation of telephone support services for informal caregivers.

Limitations of the Literature

There is very little research on telephone support for the caregiver population. Fewer than half of the primary studies on telephone support for informal caregivers have been conducted in Canada, and only one study was qualitative in nature. The qualitative study is focused on telephone support group interventions (Stewart et al., 2001), and includes the perspectives of both individuals with hemophilia and HIV/AIDS and their family caregivers.

A detailed review and critical analysis of the research on telephone support is presented in the second chapter of this dissertation. It was certainly evident that there is a lack of qualitative research exploring the one-to-one intervention of telephone support, and its ability as an intervention to assist caregivers of persons with dementia. There was also an absence of research describing the perspectives of both caregiver and telephone support provider regarding this intervention.

Study Purpose and Research Questions

The purpose of this qualitative case study is to enhance understanding of the telephone support intervention, and its ability to assist caregivers of persons with dementia. This research contributes to the existing literature in several ways. First, it is

the only qualitative study to focus on one-to-one (professional to caregiver) telephone support. Second, it is the only qualitative study of telephone support to focus on family caregivers of persons with dementia. Third, it uses a qualitative case study approach, which is considered the most valuable qualitative method for investigating the strengths and weaknesses of an intervention (Keen & Packwood, 1996) and for describing how and why interventions succeed or fail (Crabtree & Miller, 1992).

Rigorous qualitative exploration is needed to identify the dimensions of telephone support and describe the perceptions of those who receive and provide telephone support. This study will include the personal and subjective experiences of telephone support from the perspectives of both caregiver and provider, for the purpose of extending our understanding of this support intervention. The following research questions formed the basis of the study:

- 1) What are the dimensions of the telephone support intervention?
- 2) What are the experiences of caregivers of persons with dementia who receive telephone support?
- 3) What are the experiences of telephone support providers who provide telephone support to caregivers of persons with dementia?

CHAPTER TWO

A Review and Critical Appraisal of the Literature on Telephone Support for Caregivers

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**A Paper Included in the Sandwich Thesis
Submitted to the School of Graduate Studies
In Partial Fulfillment of the Requirements
For the Degree Doctor of Philosophy**

McMaster University

Hamilton, Ontario

Sept. 7, 2004

The growing elderly population, budget constraints and technological advances in North America have led to reduced inpatient hospital stays, a shortage of available nursing home beds, and an emphasis on post-acute services in home care (Merlis, 2000). This shift in care to the community has contributed to increased levels of burden on informal support networks of family and friends (Grunfeld, Glossop, McDowell, & Danbrook, 1997.) More specifically, this shift in care has placed increased demands on families trying to cope with the changing needs associated with caring for a person with progressive dementia at home, contributing to increased levels of physical, psychosocial and financial burden (Durand, Krueger, Chambers, & Grek, 1995).

Telephone support is one method of delivering information, education and psychosocial support to informal caregivers of persons with dementia, and has been proposed as a cost-effective alternative means of meeting the identified needs of caregivers (Ploeg, Biehler, Willison, Hutchison, & Blythe, 2001; Short & Saindon, 1998). In addition, recent research has supported the addition of telephone support to existing caregiver interventions, as caregivers indicate a preference for this type of service (Colantonio, Cohen, & Corlett, 1998; Colantonio, Kositsky, Cohen, & Vernich, 2001). However, there has been very little research published exploring the intervention of telephone support and the impact on the caregiving experience. Further, there has been no critical appraisal of the state of the research, or synthesis of the literature in this area. The purpose of this paper is to describe, critically review, and synthesize the existing research related to the intervention of telephone support and its impact on caregiving

experiences. This paper will conclude with implications for additional research and for the development of interventions for caregivers.

Review of the Literature

A literature search was conducted with the assistance of an expert librarian to determine the amount and type of existing research that evaluates telephone support services for caregivers of persons with chronic mental impairment. Several electronic searches were completed and eleven databases were accessed: MEDLINE (1990-2003), CINAHL (1982-2003), HealthSTAR (1975-2003), PsychINFO (1988-2003), Sociological Abstracts (1986-2003), Social Sciences Index (1983-2003), Ageline (1978-2003), Cochrane Databases of Systematic Reviews (CDSR), Cochrane Controlled Trials Register (CCTR), Database of Abstracts of Reviews of Effectiveness (DARE), and WebSpirs. The search strategies included the use of text words and medical subject headings (MeSH) to maximize precision in the literature search (ie., “telephone”, “telecare”, “teleconsultation”, “telemedicine”, “hotlines”, and “caregivers”).

Documents were initially selected if the title or abstract suggested that they contained information related to informal/family caregivers, interventions, and telephone (See Table 1 for an example of search strategy). Caregivers in this review were more than 18 years of age, and caring for either a spouse or parent with a chronic physical or mental impairment. From the articles retrieved, it was decided that the main focus would be on dementia caregivers, as dementia was the most common chronic impairment cited in the caregiver telephone support literature. Only primary studies or

Table 1 Example of Search Strategy

Database: MEDLINE <1990 to September Week 2 2003>
 Search Strategy:

- | | |
|----|---------------------------------|
| 1 | exp telemedicine/ |
| 2 | telecare.mp. |
| 3 | teleconsultation.mp. |
| 4 | exp hotlines |
| 5 | telephone/ |
| 6 | 1 or 2 or 3 or 4 or 5 |
| 7 | caregivers/ |
| 8 | exp home care services/ |
| 9 | exp home nursing/ |
| 10 | 7 or 8 or 9 |
| 11 | 6 and 10 |
| 12 | telephone.mp. or exp telephone/ |
| 13 | (phone or phoning).tw. |
| 14 | videophone.tw. and 11 |
| 15 | 12 or 13 |
| 16 | 15 and 11 |
| 17 | 14 or 16 |
-

The text words “telemedicine, hotlines, home care services, home nursing and telephone” were exploded (exp) while various other text words (tw) were mapped (mp) to define the scope of the search. The Boolean operators “or & and” were used to exclude and widen the search.

systematic reviews that were written in the English language were included. Excluded from this review were studies of caregivers of children or palliative family members. Documents were also excluded from the review if they were editorials, opinion papers or case reports.

For the purpose of trying to interpret current research on caregiver interventions, specifically the effectiveness and impact of telephone support on the caregiving experience of caregivers of persons with dementia, this literature review focused on the following three areas: systematic reviews of caregiver support interventions; systematic reviews of telephone support interventions; and primary studies of telephone support for family caregivers. The systematic reviews on caregiver support interventions and telephone support interventions are summarized, and the primary studies examining telephone support as an intervention for family caregivers are critically appraised.

Systematic Reviews of Caregiver Support Interventions

Nine systematic reviews were retrieved that focused on various interventions for caregivers (Acton & Kang, 2001; Bourgeois, Schulz, & Burgio, 1996; Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Knight, Lutzky, & Macofsky-Urban, 1993; Pusey & Richards, 2001; Roberts et al., 2000; Schulz et al., 2002; Sorenson, Pinquart, & Duberstein, 2002; Yin, Zhou, & Bashford, 2002). Of these reviews, six focused on caregivers of persons with dementia (Acton & Kang; Bourgeois et al.; Cooke et al.; Pusey & Richards; Roberts et al.; Schulz). The most recent review, which was also a meta-analysis, studied six types of caregiver interventions: psycho-educational,

supportive, respite/daycare, psychotherapy, multi-component interventions, and interventions to improve care receiver competence (Sorenson et al., 2002). The findings revealed that intervention effects were larger for increasing caregivers' knowledge/ability than for decreasing caregiver burden and depression. The review also indicated that the interventions were less effective at improving caregiver burden, depression and subjective well-being when care receivers had dementia, compared with care receivers who did not have dementia (Sorenson et al.).

Other recent systematic reviews concluded that current caregiver interventions (ie., respite, support groups, counselling, and educational sessions) have little or no effect on caregiver burden (Acton & Kang, 2001; Schulz et al., 2002; Yin et al., 2002). Some of the methodological limitations of the primary studies included in these reviews can be summarized as follows: insufficient sample size to achieve statistical power; lack of random allocation; lack of attempts to blind outcome assessment; poor description of interventions; lack of reliable and valid outcome measures; insensitivity of measures; and lack of economic evaluation (Acton & Kang; Schulz et al.; Yin et al.). None of the reviews referred specifically to telephone support as an intervention for caregivers.

Systematic Reviews of Telephone Support Interventions

A search of the literature and contact with experts revealed three systematic reviews examining the effectiveness specifically of telephone support for various groups of individuals (Cava et al., 1999; Hoxby et al., 1997; McBride & Rimer, 1999). In these reviews, telephone interventions were found to be most effective in promoting lifestyle

changes and in reducing the number of face-to-face clinical encounters for patients with chronic illnesses who were high users of health services. Again, while the three reviews suggested that telephone interventions have a positive impact on both physical and psychological health of individuals who access this type of support, none of the studies included in the reviews specifically focused on telephone support as an intervention for caregivers.

Primary Studies of Telephone Support for Family Caregivers

When the literature search was narrowed to research focusing on telephone support interventions for informal caregivers, only 13 primary studies met the inclusion criteria listed above. Twelve studies used quantitative designs and were grouped as: (a) evaluation studies (Brown et al., 1999; Coyne, Potenza, & Broken Nose, 1995; Davis, 1998; Gitlin et al., 2003; Goodman & Pynoos, 1990; Grant, Elliot, Weaver, Bartolucci, & Newman Giger, 2002; Hartke & King, 2003; Mahoney, Tarlow, & Jones, 2003; Strawn & Hester, 1998); or (b) descriptive studies (Coyne, 1991; Silverstein, Kennedy, & McCormick, 1993; Skipwith, 1994). One study used a qualitative approach (Stewart et al., 2001).

Summary of Study Characteristics

The studies were conducted between 1990-2003 (See Appendix A for summary of studies reviewed). Only two of the studies were conducted in Canada (Brown et al., 1999; Stewart et al., 2001) and the remainder were conducted in the U.S.A. There was variation between studies in sample characteristics. For example, eight studies included

caregivers of persons with a type of dementia (Coyne, 1991; Coyne et al., 1995; Davis, 1998; Gitlin et al., 2003; Goodman & Pynoos, 1990; Mahoney et al., 2003; Silverstein et al., 1993; Strawn & Hester, 1998); two studies included caregivers of persons who had suffered a stroke (Grant et al., 2002; Hartke & King, 2003); one study included carers of persons with an acquired brain injury (Brown et al., 1999); one study included caregivers of persons with hemophilia and AIDS (Stewart et al., 2001); and one study included caregivers of disabled elders (Skipwith, 1994). The studies reviewed included caregiver samples that were primarily female and Caucasian.

Of the thirteen studies reviewed, four described telephone support group interventions, one defined telephone support as a computer-mediated interactive voice response system, one study used telephone support only as a control intervention, and four examined telephone support in the form of “hotlines”. Only three studies focused on a one-to-one telephone support intervention. Types of telephone contact also varied across studies from the provision of information and emotional support, to coaching problem-solving and coping strategies, establishing educational support groups and evaluating help-lines and a computer-mediated interactive voice response system. Calls were initiated by both telephone support provider and caregiver, and varied in length of call (15 minutes to 2 hours) and duration of telephone support service (8 weeks to 2 years). For the most part, telephone support providers were health care professionals, however in one study, peers provided the support (Goodman & Pynoos, 1990). One study included both professional and peer telephone support providers (Stewart et al., 2001).

The evaluation studies of telephone support included six randomized controlled trials (Coyne et al., 1995; Gitlin et al., 2003; Goodman & Pynoos, 1990; Grant et al., 2002; Hartke & King, 2003; Mahoney et al.), one quasi-experimental study (Brown et al., 1999), and two studies using before/after designs (Davis, 1998; Strawn & Hester, 1998). All evaluation studies were appraised for methodological rigor.

Methodological Rigor of the Evaluation Studies

An assessment tool by Cullum (2001) was used in the appraisal of the nine evaluation studies on telephone support. Methodological criteria including study design, source of biases, outcome measures and assessment, and sample characteristics were involved in the appraisal (See Table 2 for the criteria). In summary, the appraisal of the literature revealed only three studies that were particularly well conducted (See Appendix B for appraisal). The studies by Gitlin et al. (2003), Grant et al. (2002), and Mahoney et al. (2003) were considered to be of high quality as they included randomization procedures, adequate descriptions of methods and sample characteristics, blinding (Gitlin et al. 2003; Grant et al. 2002), and repeated measure approaches for longitudinal data (Grant et al., 2002; Mahoney et al. 2003). Each study openly acknowledged its limitations, which included the inability to disaggregate which treatment elements were most important for decreasing burden (Gitlin et al., 2003), a limited focus on caregiving variables such as duration of caregiving experience and the number of other caregivers involved in the experience (Grant et al.), and sample under-

Table 2: Evaluation of Studies of Treatment or Prevention Interventions

1. Are the results of the study valid?
 - a. What is the design, and is it the most rigorous for the question being asked?
 - b. Are there potential sources of selection bias?
 - i. Was the assignment of patients to treatments randomized?
 - ii. Was follow-up sufficiently long and complete?
 - iii. Were patients, clinicians, outcome assessors, and data analysts blinded to patient allocation?
 - c. Were groups similar at the start of the study?
 2. What are the results?
 - a. Were treatment outcomes measured appropriately?
 - b. Were the results statistically significant?
 - c. How precise is the estimate of the treatment effect?
 3. Can I apply the results to my patients?
 - a. Were study participants described in sufficient detail?
-

Cullum, (2001).

enrolment (Grant et al.; Mahoney et al.). Each of the three studies differed in their ability to achieve statistically significant results.

Limitations of the remaining evaluation studies that were appraised included inadequate descriptions of sample and methods, lack of randomization and blinding procedures, multiple sources of bias, and small sample sizes. Small sample sizes have a risk of failing to demonstrate a real difference (Bowling, 1997). Each study reviewed included outcome measurement tools that were reliable and valid, however most studies chose to focus only on the negative effects associated with the caregiving experience.

Results from the Primary Studies

Because of the limited number of studies on telephone support for caregivers, the results from all of the primary studies, regardless of the strength of the research, have been included in this review. Results from all of the randomized controlled trials indicated that telephone contact with informal caregivers increased use of community services and increased perceived social supports (Coyne et al., 1995; Gitlin et al., 2003; Goodman & Pynoos, 1990; Grant et al., 2002; Hartke & King, 2003; Mahoney et al., 2003). However, findings from two of the studies were mixed on the outcome of caregiver burden. A study by Goodman and Pynoos (1990) that focused on family caregivers of persons with Alzheimer disease found no relationship between telephone support and relief from caregiver burden, while a similar study by Coyne et al. (1995) found that telephone support decreased caregiver burden. Both studies used Zarit's

Burden Interview (Zarit & Zarit, 1990) to measure burden among the informal caregivers.

The randomized controlled trial by Mahoney et al. (2003) also focused on family caregivers of persons with Alzheimer disease, but investigated the effects of a computer-mediated interactive voice response system. Results indicated that the wives who exhibited low mastery and high anxiety benefited the most from the automated telephone intervention. An earlier study of this intervention found that the total time caregivers accessed this service averaged 55 minutes per user, but the overall preference was for human interaction (Mahoney, Tarlow, Jones, Tennstedt, & Kasten, 2001).

The largest randomized controlled trial (RCT) of telephone support to date (Gitlin et al., 2003) involved 1,222 caregivers of persons with Alzheimer Disease and related dementia across six different sites. The REACH (Resources for Enhancing Alzheimer's Caregiver Health) project compared five interventions (individual information and support strategies, group support and family systems therapy, psycho-educational and skills-based training, home-based environmental interventions, and enhanced technology support systems). All five interventions were compared to "minimal support conditions" which were defined as telephone support and written information on dementia. Findings suggested that interventions for caregivers of persons with dementia should be multi-component and tailored, as there were no statistically significant effects for any one intervention for the outcomes of burden and depression. There was a statistically significant pooled treatment effect for burden (albeit quite small), but not for depression (Gitlin et al., 2003).

The RCT by Grant et al., (2002) examined the effectiveness of social problem-solving therapy delivered by telephone for family caregivers of stroke victims. The study findings revealed that this intervention not only improved caregiver problem-solving skills, preparedness, vitality, social functioning and mental health, but also decreased depression and role isolation (Grant et al.).

Hartke and King (2003) employed an RCT wait list control method (which ensures that all participants have the opportunity to be involved in the treatment program) to evaluate telephone support for family caregivers of persons with a stroke. The results revealed that the majority of the caregivers in the telephone educational support group indicated improved health, stress management, and an increase in caregiver competence.

Brown et al. (1999) used a quasi-experimental design, and concluded that telephone support services offer a method of providing informational and emotional assistance to rural and isolated family caregivers of persons with a brain injury that is just as effective as on-site support groups. Two studies with a before/after design (Davis, 1998; Strawn & Hester, 1998) focused on family caregivers of persons with dementia, and both studies reported a reduction in depressive symptoms, an increase in social supports accessed, and an increase in life satisfaction as a result of the telephone support intervention.

There were three descriptive studies on telephone support (Coyne, 1991; Silverstein et al., 1993; Skipwith, 1994). Two of the descriptive studies (Coyne, 1991; Silverstein et al.) indicated that a telephone-based information and referral line was

useful in disseminating knowledge about resources to family caregivers of persons with Alzheimer Disease and related dementia. People often called the help-line for information about dementia, Adult Day Programs, and existing support groups and services in the area. The final descriptive study (Skipwith) outlined case examples that demonstrated the potential for telephone counselling to become an economical, efficient, outcome-based intervention strategy for use with caregivers of all elderly persons.

The Qualitative Study

Only one qualitative study explored the telephone support intervention (Stewart et al., 2001). This study focused on telephone support as a group intervention, and concluded that telephone support groups had a positive impact on meeting some of the needs of informal caregivers of men with hemophilia and HIV/AIDS. Telephone support groups decreased their feelings of isolation and loneliness, however the participants felt that the intervention should have been longer than 12 weeks (Stewart et al.).

Criteria by Russell and Gregory (2003) were used to critique the qualitative research study (See Table 3 for criteria). This study was well conducted and credible as it described most of the components of the study in adequate detail, including strategies for limiting bias (inter-rater agreement), and acknowledged the ethical considerations and study limitations (i.e., bias introduced during support group discussion through agenda setting and topic coverage) (See Appendix C for Appraisal) (Stewart et al., 2001.)

Table 3 Evaluation of Qualitative Research Studies

1. Are the results of the study valid?
 - a. Is the research question/purpose of the study clearly stated?
 - b. Is the qualitative methodology appropriate for the question?
 - c. Was the method of sampling appropriate for the question and design?
 - d. Was data collection described in sufficient detail?
 - e. Were data analyzed appropriately, and strategies for ensuring rigour discussed?
 - f. Was relevant information about the investigator given, and their perspective(s) declared?
 2. What are the results?
 - a. What were the results?
 - b. Were the conclusions appropriate and consistent with the data?
 3. Can I apply the results to my clients?
 - a. Was the importance of the research addressed?
 - b. Does the research enhance my understanding of the topic?
-

Adapted from Russell & Gregory, 2003.

Synthesis of the Research

After reviewing existing research on caregiver support interventions, telephone support interventions and telephone support for caregivers, several conclusions can be drawn. First, in regard to all existing caregiver support interventions, the findings revealed that current interventions (ie., respite, support groups, counselling and educational sessions) have little or no effect on caregiver burden (Acton & Kang, 2001; Gitlin et al., 2003; Schulz et al., 2002; Sorenson et al., 2002; Yin et al., 2002). This could be the result of interventions failing to decrease levels of caregiver burden, or the result of poor instrument sensitivity. For example, the Zarit Burden Interview (BI) (Zarit & Zarit, 1990) has been the measurement of choice in previous literature, but it has demonstrated lower effect sizes than other measures of burden, and has been criticized for its summary score and for its potential to mask dimension-specific patterns of caregiving impact (George & Gwyther, 1986). Caution must be used when reviewing studies using the BI as there is no assessment of caregiver-centred problems that may contribute to feelings of burden and distress, and the BI may also be criticized for assuming that the presence of a problem equates with distress or despair (Kane & Kane, 2000). More accurate and sensitive measurement of caregiver outcomes is required to evaluate the impact of caregiver interventions.

Second, it is important to acknowledge and measure more than just the negative effects of caregiving (ie., burden and depression), including a focus on interventions or strategies that have the most positive effect on the caregiver (Kramer, 1997). The most current research reviewed indicates that existing interventions have a larger impact on a

caregiver's knowledge and ability (or levels of mastery) than on negative variables of burden and depression (Acton & Kang, 2001; Schulz et al., 2002; Sorenson et al., 2002; Yin et al., 2002). Therefore, existing and future caregiver support interventions should continue to acknowledge and foster a caregiver's abilities and not just attempt to "alleviate or eliminate" the negative effects associated with the caregiving experience. This is consistent with current research that has revealed that quality caregiving can co-exist with caregiver burden, and that given the chronic nature of older people's health conditions, caregiving burden may not be readily reducible (Greenberger & Litwin, 2003).

Third, this review reinforces the fact that existing caregiver interventions (ie., support groups, respite, educational sessions) are less effective at improving levels of burden, depression and subjective well-being when care receivers had dementia, compared with care receivers who did not have dementia. Research evidence has demonstrated the greater demands faced by caregivers of persons with dementia when compared with caregivers of persons with other chronic illnesses. For example, more time is required to provide care and supervision for persons with dementia, who often demonstrate disruptive behaviours (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). As a result, caregivers of persons with dementia tend to experience poorer health, increased levels of burden, anxiety and depression (Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000). This suggests that those who care for persons with dementia may require a different intervention strategy than their counterparts.

None of the systematic reviews of caregiver support interventions focused specifically on the intervention of telephone support, and none of the systematic reviews of telephone support focused specifically on telephone support for caregivers. However, the reviews on telephone support as an intervention did reveal the positive impact on both the physical and psychological health of individuals who access this type of support. More specifically, it was most effective in promoting lifestyle changes and in reducing the number of face-to-face clinical encounters for patients with chronic illnesses who were high users of health services.

These findings highlight the potential for telephone support to have a positive impact on caregivers, since caregiving has the potential to negatively impact both the physical and mental health of the caregiver (George & Gwyther, 1986). The literature suggests that telephone support has the potential to positively influence a dementia caregiver's knowledge and ability (or mastery), and may positively affect their physical and psychological health. However, it was somewhat difficult to confirm this from the primary research studies on caregiver telephone support reviewed. First, only two of the nine evaluation studies reviewed focused on caregivers of persons with a dementia (Gitlin et al., 2003; Mahoney et al., 2003), and these studies investigated the use of either computer-mediated interactive voice response systems (which are not a standard form of telephone support), or used telephone support as a control intervention. Second, the only qualitative study that has been completed to date focused on telephone support groups for informal caregivers of men with hemophilia and HIV/AIDS (Stewart et al., 2001). Although the evidence suggests the potential benefits of telephone support for other

caregiving groups, there remains a lack of both quantitative and qualitative research evaluating and exploring the intervention of telephone support for family caregivers, specifically for caregivers of persons with dementia.

Finally, the reviewed literature failed to answer two key questions related to telephone support: What are the dimensions of the telephone support intervention? What are the experiences of caregivers and telephone support providers with this intervention?

Research Implications

Further research is required to understand the effectiveness and perceived impact of caregiver telephone support, specifically for caregivers of persons with dementia. Ideally, studies of large scale and high quality design are needed to produce more definitive conclusions about the effectiveness of telephone support for caregivers of persons with dementia. However, before research can successfully determine whether or not telephone support is an effective intervention for dementia caregivers, an in-depth understanding of the nature of telephone support, as well as an understanding of the perceptions of those involved must be acquired.

Credible qualitative research would be the best method to heighten understanding of the experiences of telephone support for caregivers of persons with dementia. As in all qualitative inquiry, there is an emphasis on understanding the social world from the perspectives of those who participate in it, and it would be beneficial to assess the experiences of both the receivers (caregivers) and the providers of the telephone support intervention. Case study methodology is considered the most valuable qualitative design

when investigating the strengths and weaknesses of an intervention (Keen & Packwood, 1996) and when evaluating health care services (Crabtree & Miller, 1992).

Finally, caregiving can be conceptualized as a complex process characterized by multiple dimensions. Recent research has elaborated on the experience of caregiving by examining not only the negative consequences of caregiving, but also exploring the positive psychological factors associated with providing care to a family member or friend (Cohen, Colantonio, & Vernich, 2002). Future research examining caregiver support interventions should continue to acknowledge both the positive and negative dimensions of the caregiving experience, and strive to foster the positive outcomes while abating the negative consequences associated with providing care to a loved one.

One of the challenges that health care professionals will continue to face in the future will be trying to meet the needs of family caregivers. After reviewing and appraising current literature on telephone support for caregivers, it is evident that there is a lack of rigorous and credible research evidence. Although current literature reveals that the intervention of telephone support has had positive outcomes on patients and caregivers with a variety of chronic illnesses, the overall effectiveness and perceived impact of this intervention with caregivers of persons with dementia is still relatively unknown. Further research is clearly needed to better understand the dimensions of one-to-one telephone support, and its strengths and limitations as perceived by both caregivers and providers involved in this intervention. This new level of understanding

can then assist with the planning, implementation, and evaluation of caregiver support services that effectively meet the unique needs of caregivers of persons with dementia.

References

- Acton, G., & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. *Research in Nursing & Health, 24*, 349-360.
- Beeson, R., Horton-Deutsch, S., Farran, C., & Neundorfer, M. (2000). Loneliness and depression in caregivers of persons with Alzheimer's disease or related disorders. *Issues in Mental Health Nursing, 21*(8), 779-806.
- Bourgeois, M., Schulz, R., & Burgio, L. (1996). Interventions for caregivers of patients with Alzheimer's Disease: A review and analysis of content, process and outcomes. *International Journal of Aging and Human Development, 43*, 35-92.
- Bowling, A. (1997). *Research methods in health: Investigating health and health services*. Philadelphia: Open University Press.
- Brown, R., Pain, K., Berwald, C., Hirschi, P., Delehanty, R., & Miller, H. (1999). Distance education and caregiver support groups: Comparison of traditional and telephone groups. *Journal of Head Trauma Rehabilitation, 14*(3), 257-268.
- Cava, M., Wade, K., Cho, S., Dwyer, J., Johnson, I., & Lee-Han, H. (1999). *The effectiveness of telephone intervention as a delivery strategy within the scope of public health nursing practice: A systematic overview*. Toronto, Ontario: Toronto Public Health Research, Education and Development Program and the Nursing Division.
- Cohen, C., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: rounding out the caregiver experience. *International Journal of Geriatric Psychiatry, 17*, 184-188.
- Colantonio, A., Cohen, C., & Corlett, S. (1998). Support needs of elderly caregivers of persons with dementia. *Canadian Journal of Aging, 17*(3), 330-345.
- Colantonio, A., Kositsky, A., Cohen, C., & Vernich, L. (2001). What support do caregivers of elderly want? Results from the Canadian study of health and aging. *Canadian Journal of Public Health, 92*(5), 376-379.
- Cooke, D., McNally, L., Mulligan, K., Harrison, M., & Newman, S. (2001). Psychosocial interventions for caregivers of people with dementia: A systematic review. *Aging and Mental Health, 5*, 120-135.

- Coyne, A. (1991). Information and referral service usage among caregivers for dementia patients. *The Gerontologist*, 31, 384-388.
- Coyne, A., Potenza, M., & Broken-Nose, M. (1995). Caregiving and dementia: The impact of telephone helpline services. *American Journal of Alzheimer's Disease*, 10(4), 27-32.
- Crabtree, B., & Miller, W. (1992). *Doing qualitative research*. Newbury Park, CA: Sage.
- Cullum, N. (2001). Evaluation of studies of treatment or prevention interventions. *Evidence Based Nursing*, 3, 100-102.
- Davis, L. (1998). Telephone-based interventions with family caregivers: A feasibility study. *Journal of Family Nursing*, 4, 255-270.
- Durand, P., Krueger, P., Chambers, L., & Grek, A. (1995). Predictors of caregivers' dissatisfaction with community long-term care services for seniors: Results from the Canadian study of health and aging. *Canadian Journal of Public Health*, 86(5), 325-332.
- George, L., & Gwyther, L. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist*, 26, 253-259.
- Gitlin, L., Burgio, L., Mahoney, D., Burns, R., Zhang, S., Schulz, R., Belle, S., Czaja, S., Gallagher-Thompson, D., Hauck, W., & Ory, M. (2003). Effect of multicomponent interventions on caregiver burden and depression: The REACH multi-site initiative at 6-month follow-up. *Psychology & Aging*, 18(3), 361-374.
- Goodman, C., & Pynoos, J. (1990). A model telephone information and support program for caregivers of Alzheimer's patients. *The Gerontologist*, 30, 399-404.
- Grant, J., Elliot, T., Weaver, M., Bartolucci, A., & Newman Giger, J. (2002). Telephone interventions with family caregivers of stroke survivors after rehabilitation. *Stroke*, 33, 2060-2065.
- Greenberger, H., & Litwin, H. (2003). Can burdened caregivers be effective facilitators of elder care-recipient health-care? *Journal of Advanced Nursing*, 41, 332-341.
- Grunfeld, E., Glossop, R., McDowell, I., & Danbrook, C. (1997). Caring for elderly people at home: The consequences to caregivers. *Canadian Medical Association Journal*, 157, 1101-1105.

- Hartke, R., & King, R. (2003). Telephone group intervention for older stroke caregivers. *Topics in Stroke Rehabilitation*, 9, 65-81.
- Hoxby, H., Roberts, J., Browne, G., Pallister, R., Gafni, A., & Streiner, D. (1997). *Telephone nursing support: Let's talk*. Working paper 97-2. Hamilton, Ontario: System Linked Research Unit, McMaster University.
- Kane, R., & Kane, R. (2000). *Assessing older persons: Measures, meaning, and practical implications*. New York: Oxford University Press.
- Keen, J. & Packwood, T. (1996). Case study evaluations. In N. Mays & C. Pope (Eds.), *Qualitative research in healthcare*. London: B.M.J. Publishing Group.
- Knight, B., Lutzky, S., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *Gerontologist*, 33, 240-248.
- Kramer, B. (1997). Gain in the caregiving experience: Where are we? What next? *The Gerontologist*, 37, 218-232.
- Mahoney, D., Tarlow, B., & Jones, R. (2003). Effects of an automated telephone support system on caregiver burden and anxiety: Findings from the REACH for TLC Intervention Study. *The Gerontologist*, 43,(4), 556-567.
- Mahoney, D., Tarlow, B., Jones, R., Tennstedt, S., & Kasten, L. (2001). Factors affecting the use of a telephone-based intervention for caregivers of people with Alzheimer's disease. *Journal of Telemedicine and Telecare*, 7(3), 139-48.
- McBride, C., & Rimer, B. (1999). Using the telephone to improve health behaviour and health service delivery. *Patient Education Counselling*, 37, 3-18.
- Merlis, M. (2000). Caring for the frail elderly: An international review. *Health Affairs*, 19, 141-149.
- Ory, M., Hoffman, R., Yee, J., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist*, 39, 177-185.
- Ploeg, J., Biehler, L., Willison, K., Hutchison, B., & Blythe, J. (2001). Perceived support needs of family caregivers and implications for a telephone support services. *Canadian Journal of Nursing Research*, 33(2), 43-61.

- Pusey, H., & Richards, D. (2001). A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging and Mental Health*, 5, 107-119.
- Roberts, J., Brown, G., Gafni, A., Varieur, M., Loney, P., & deRuijter, M. (2000). Specialized continuing care models for persons with dementia: A systematic review of the research literature. *Canadian Journal on Aging*, 19, 106-126.
- Russell, C., & Gregory, D. (2003). Evaluation of qualitative research studies. *Evidence Based Nursing*, 6, 36-40.
- Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L., Belle, S., Burgio, L., Gitlin, L., Coon, D., Burns, R., Gallagher-Thompson, D., & Stevens, A. (2002). Dementia caregiver intervention research: In search of clinical significance. *The Gerontologist*, 42(5), 589-602.
- Short, L., & Saindon, E. (1998). Telehomecare: Rewards and risks. *Caring*, 17, 36-42.
- Silverstein, N., Kennedy, K., & McCormick, D. (1993). A telephone helpline for Alzheimer's disease: Information, referral, and support. *American Journal of Alzheimer's Care and Related Disorders and Research*, 8(5), 28-36.
- Skipwith, D. (1994). Telephone counselling interventions with caregivers of elders. *Journal of Psychosocial Nursing*, 32, 7-12.
- Sorenson, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42(3), 356-372.
- Stewart, M., Hart, G., Mann, K., Jackson, S., Langille, L., & Reidy, M. (2001). Telephone support group interventions for persons with hemophilia and HIV/AIDS and family caregivers. *International Journal of Nursing Studies*, 38, 209-225.
- Strawn, B., & Hester, S. (1998). Telecare: A social support intervention for family caregivers of dementia victims. *Clinical Gerontologist*, 18, 66-69.
- Yin, T., Zhou, Q., & Bashford, C. (2002). Burden on family members - Caring for frail elderly: A meta-analysis of intervention. *Nursing Research*, 51(3), 199-208.
- Zarit, S., & Zarit, J. (1990). *The memory and behaviour problems checklist and the burden interview*. Penn State: Gerontology Centre.

CHAPTER THREE

Qualitative Inquiry Among Dementia Caregivers: A Cogent Source, Yet Challenging

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A Paper Included in the Sandwich Thesis
Submitted to the School of Graduate Studies
In Partial Fulfillment of the Requirements
For the Degree Doctor of Philosophy

McMaster University

Hamilton, Ontario

Sept. 7, 2004

Qualitative Research Methods

After reviewing literature detailing caregiver interventions, it was apparent that there is a need for qualitative exploration of the informal caregiver experience with telephone support. The following study is a unique contribution to the existing literature as it is the only qualitative study to date to focus on one-to-one (professional to caregiver) telephone support for family caregivers of persons with dementia. It uses a qualitative case study approach, which is considered the most valuable qualitative method for investigating the strengths and weaknesses of an intervention (Keen & Packwood, 1996).

This paper outlines the three research questions that provided the foundation of the study, and describes the case study design, methods, and procedures used to enhance the methodological rigor of the study. Second, this paper highlights the challenges encountered during the process of data collection and analysis, and the strategies used to overcome such obstacles.

Study Purpose and Research Questions

The purpose of this research study was to understand the intervention of one-to-one telephone support, as provided by professionals to informal caregivers of persons with dementia. The emphasis was on comprehending the intervention from the point of view of those who use the service, and those who provide it.

The following questions formed the basis of the study:

- 1) What are the dimensions of the telephone support intervention?
- 2) What are the experiences of caregivers of persons with dementia who receive telephone support?
- 3) What are the experiences of telephone support providers who provide telephone support to caregivers of persons with dementia?

The Qualitative Case Study Approach

A qualitative case study approach was chosen to guide the process of data collection and analysis. This approach is comprised of a bounded system, with the focus being on either the case or an issue that is illustrated by the case. Following Stake's (1995) approach to case study methodology, this approach was chosen to capture the complexity of the intervention of telephone support. A case study approach is particularly valuable when evaluating health care services as it is capable of capturing the complexity, and achieving enhanced understanding of an intervention or program (Crabtree & Miller, 1992).

The Case

For the purpose of understanding telephone support, the case was defined as the telephone support intervention itself. Telephone Support can be defined as assistance provided through a telephone conversation. It is a service that can be initiated by either provider or caregiver (See Appendix D for glossary). The case was bounded by

geographical location and organization (service provided by the Alzheimer Society and/or a community nursing agency that offers an Alzheimer Day and Caregiver Support Program). These two organizations were chosen not only because they provided telephone support in south central Ontario, but also because they varied in the type of intervention offered – one offered support that was anonymous and caregiver initiated, and the other organization offered telephone support as follow-up to their other support programs (ie., Alzheimer Day Program), and could be initiated by either caregiver or telephone support provider. The case was also bounded by time (receipt of telephone support within the last year), by provider (delivered by a health professional), by the caregiver (caring for a person more than 50 years of age with dementia), and by the investigator's definition of telephone support.

Entry Into Field

As the result of increased demands and burden associated with the caregiving experience, caregivers are a vulnerable population. Understandably so, both organizations were very protective of their caregivers, and prior to the selection of the participants, I met with the Executive Directors of the Alzheimer Society and of the Alzheimer Day Program to discuss the goals and main purpose of the study. After both Executive Directors had agreed to partake in the study, I outlined the inclusion and exclusion criteria for the participants, and the Directors identified individuals who were eligible to participate in the study.

Sampling Frame

Criterion and convenience sampling procedures were used to identify participants for inclusion in this case study (Miles & Huberman, 1994). A criterion sampling strategy was used to select participants who met the following criteria: the caregiver was 18 years of age or older; had assumed the majority of caregiving duties for a family member with dementia; was able to communicate in English; had received telephone support at some point within the last year from either of the two organizations mentioned above; and resided within south central Ontario. Caregiver participants were excluded from the study if they were caring for a person with a dementia related to malignancy and/or medication.

The inclusion criteria for telephone support providers included: health care professionals affiliated with one of the two above community organizations; who were able to communicate in English; and had provided telephone support to caregivers of persons with dementia within the last year. All non-professional telephone support providers (ie., friends and peers from support groups) were excluded from this study. A convenience sampling strategy was also used to identify caregivers and providers who were available and willing to participate between the months of June and December 2003.

Recruitment

Once interested caregivers and providers were identified, the Directors contacted each of the participants by phone to inform them of the study and request their involvement, using a script that was created to facilitate the process (See Appendix E for

the script). The names and contact information for each participant were then forwarded via email, and the participants were contacted by telephone soon afterwards to introduce them to the study, and ask for their consent to participate in the interview (See Appendix F for verbal consent form). After participants agreed to participate, a package was mailed containing a cover letter, a descriptive overview of the project, and a consent form (See Appendices G, H, and I for cover letter, overview, and consent form). The consent forms outlined the details of the study, measures that would ensure confidentiality of the information collected through the interviews, and a telephone number to contact if necessary. A second phone call was made 24 hours prior to the arranged interview to confirm the participant's willingness to be involved.

Data Collection

A qualitative case study approach uses an array of data sources as the researcher attempts to build an in-depth picture of each case (Creswell, 1998). In this study of telephone support, two main sources of data were used: (a) documentation of contextual information, and (b) interview data.

Contextual Information

Contextual information was collected prior to, and following each interview session. Documentation occurred through: (a) demographic information pertaining to each participant and the agency they were affiliated with; (b) researcher field notes and memos; and (c) a contact summary form.

Demographic Information. Demographic information such as the age, gender, and occupation of each provider was collected, as well as information describing the two telephone support organizations involved in the study. Data pertaining to each of the organizations and their caregiver support programs were collected prior to the recruitment of participants in order to determine the suitability of agency involvement in the study. Afterwards, this information was helpful in achieving an enhanced understanding of the intervention of telephone support, and the experiences of both the caregivers and the providers with this and other forms of support.

Additionally, the purpose of collecting demographic information on the caregiving experience was crucial in understanding why this intervention was sought out and accessed in the first place (Noonan & Tennstedt, 1997; Pearlin, Mullan, Semple, & Skaff, 1990). Data were collected by the investigator prior to each caregiver interview session, and included demographic details such as the age and gender of both the caregiver and the care receiver, employment status, and living arrangement (See Appendix J for collection tool).

Researcher Field Notes and Memos. Field notes and researcher memos were maintained throughout the research process for the purpose of documenting any decision points or impressions of the data, unexpected findings, or frustrations and challenges I encountered. This source of documentation included information additional to that collected prior to, and/or during the interview sessions. The data from the notes and the memos were not directly related to the three main research questions, however were considered as significant in understanding and interpreting the overall findings of this

study. Research memos were also maintained for the purpose of identifying and acknowledging previous knowledge, subjective responses, as well as the potential for influencing the research process and overall interpretations and analysis of the data.

Contact Summary Form. Once all of the contextual information and interview data had been collected, observation details of each participant and setting were recorded using a contact summary form (Miles & Huberman, 1994). This form assisted in the organization of thoughts and key themes that were referred to while analyzing the data (See Appendix K for contact summary form). Collecting all observational data related to the interview is “part of the artistry” of case study research (Stake, 1995, p.66).

Interview Data

Interview data included: (a) audio-taped face-to-face or telephone interviews with caregivers, and (2) audio-taped face-to-face interviews with professionals who provide telephone support. One of the professionals interviewed was an Executive Director of one of the two organizations involved in the study who founded the Telephone Support Program and also provided this form of support.

Interviews with Caregivers. A total of 8 caregiver interviews were conducted. All caregivers were female and between the ages of 50 and 80 years old. Caregivers were at various stages of caregiving. One had just begun caregiving, two had been doing it for three to five years, three were in the process of finding a long-term care bed at a nursing home for their loved ones, one had just moved the care recipient to a nursing home facility, and one had recently experienced the death of the care recipient.

Five interviews were conducted in the homes of the caregivers, at their request. All of these interviews were audio-taped. Two interviews took place over the phone, and only one was audio-taped. The first telephone interview was not audio-taped as the caregiver provided very short notice of her availability, and the necessary equipment to record a telephone interview had not yet been obtained. The only other interview that was not audio-taped occurred at a local coffee shop, at the request of the caregiver. Detailed notes were recorded of the two interviews that were not audio-taped.

The interviews ranged from 30-90 minutes in length. The semi-structured questionnaire consisted of 14 questions (See Appendix L for interview guide for caregivers). Half of the questions inquired about the caregiving experience in general, while the other half focused on the telephone support that they had accessed in the past and/or continued to access. The discussion was semi-structured to support a more natural, conversation-like interview. This allowed the participants to speak as much or as little as they desired (Jarrett, Payne, & Wiles, 1999).

Interviews with Providers. Interviews were also conducted with four providers of telephone support. A telephone support provider was identified as a health care professional affiliated with a community organization that provides telephone support (as an employee, volunteer, or executive director) (See Appendix M for interview guide for providers). Three of the providers were from the Alzheimer Society; two had non-nursing backgrounds, and one was a registered nurse and the previous Executive Director of the organization. The fourth provider was a nurse from the Alzheimer Day Program. Three of the interviews were conducted at the offices of the providers, and one interview

occurred at the home of the provider. These locations were requested by the participants, and were based on their levels of comfort and convenience.

Similar to the caregiver interviews, the interviews with the providers ranged from 30 to 90 minutes in length, and were semi-structured to support a more natural, conversation-like interview. The interview guide for the providers consisted of 12 questions: half of these inquired about their experiences with telephone support, and the other half focused on the intervention itself. Again, notes were taken and all interviews were audio-taped.

Protection of Participant's Rights and Ethical Considerations

The qualitative research interview is an extremely valuable tool that warrants a careful and thorough explanation of the procedure to be employed (Plant, 1996). Since some of the questions were related to potentially sensitive issues, great care was taken to ensure that all participants in this study were truly willing to participate and informed of measures to ensure confidentiality. Before conducting this qualitative study, approval was granted by the thesis committee and by the Faculty of Health Sciences, Research Ethics Board (R.E.B). In addition, both written and verbal consent were obtained from each participant prior to conducting the interviews, and it was made clear that they had the right to withdraw at any time from the interview, or to postpone it. All participants were informed that they had the right to refuse to participate in the study, and that if they chose to do so, the refusal would not affect the services they were currently receiving from the involved agencies. Permission to audio-tape was also received prior to each

interview session.

The participants were informed that all information was anonymous. Any names on the tapes or other materials associated with the project would be removed and/or concealed. Information provided would be combined with information from other people and used to describe groups of caregivers, not just an individual caregiver. The participants were also informed that all tapes and written documents would be stored in a locked filing cabinet, to which only the three members of my research committee and myself would have access.

Strategies to Promote Methodological Rigor

Various procedures were incorporated into the research process to help “validate” the collected data and ensure the credibility and trustworthiness of the research findings. In keeping with Stake’s (1995) recommendations, these included: (a) triangulation of data sources and researcher; (b) member-checking; and (c) the development of a clear and detailed audit trail, including detailed research memos.

Triangulation

Stake (1995) describes triangulation as “points of intersection” or agreement, for the purpose of establishing meaning of an observation. To gain the needed confirmation or to increase the credibility in the interpretation, several triangulating strategies can be used. This study allowed for two sources of triangulation to be used: data triangulation and investigator triangulation.

Data Triangulation. Typically, data triangulation involves the use of evidence from different sources to shed light on a theme or perspective (Stake, 1995). In this study, perspectives of experiences with telephone support were collected from two very different data sources - caregivers and telephone support providers. To increase the level of understanding of telephone support even further, data from caregivers at various stages of the caregiving experience were collected, including those whose caregiving experience had terminated and those whose experience had just begun. The perspectives of telephone support providers were captured in data from a previous Executive Director and founder of a telephone support service, in addition to current providers of the service.

Investigator Triangulation. The study also incorporated investigator triangulation into the research process. All of the interview transcripts and codebooks were reviewed by three experienced qualitative investigators for the purpose of “validating” the main themes and interpretations of the principal investigator. Both forms of triangulation contributed to the methodological rigor of the study by enhancing the credibility of the study.

Member Checking

Another source of data validation according to Stake (1995) is member checking, in which participants are asked to examine rough drafts of the researcher’s work and provide critical observations or interpretations as necessary (Stake). The preliminary themes and interpretations of the data were presented to one of the study’s participants: the telephone support provider who was the Executive Director of one of the

organizations involved in the study, who had both founded the telephone support program and provided the service as well. The purpose of this strategy was to ask the participant to review the material for “accuracy and palatability” (Stake), further enhancing the credibility of this study.

Audit Trails and Research Memos

As suggested by Stake (1995), a clear and easy-to-follow audit trail was maintained throughout this research process to assist with the confirmability of the findings. The trail consisted of a filing system comprised of all research related documents (ie., contact summary and demographic forms, interview transcripts and tapes), contact numbers, consent forms, expense receipts, a calendar list of dates and descriptions of every meeting and interview related to the project, and very detailed research memos.

Demographic data revealing background characteristics of caregivers and providers were collected for the purpose of contributing to a fuller understanding of the experience with telephone support. Rich, thick descriptions of the contexts of each caregiver situation and experience were incorporated in the analysis of the data and described in the narrative of this study for the purpose of ensuring that the findings are transferable to other similar settings and populations (Lincoln & Guba, 1985; Stake, 1994).

The aim of qualitative case study research is not to discover, but to construct a clearer and more sophisticated reality. There was no way to totally eliminate personal

influences on the data collected and analyzed, but being reflexive through research memos was an ideal strategy for identifying and incorporating any personal perspectives into this study without compromising the research (Maxwell, 1960). Reflexivity has been described as “continual evaluation of subjective responses, inter-subjective dynamics, and the research process itself” (Finlay, 2002, p.532).

Data Management

The audio-taped interviews were transcribed verbatim by a professional. The transcripts of each interview were checked with the audio-tapes, to verify the wording and content. The analysis of data began with this process of cleaning the data.

Data from the researcher field notes and memos were also reviewed, as well as the information from the contact summary forms. This contextual information was summarized and categorized into themes that were eventually combined with the themes from the interview data. Demographic information pertaining to each participant was summarized in chart form, and is included in the Findings Paper (Chapter Four) of this thesis, as is the information describing the two organizations involved in this study.

Data Analysis

The purpose of this study was to acquire an enhanced understanding of telephone support as an intervention for caregivers of persons with dementia. As such, the analysis proceeded according to the four stages of interpretation proposed by Stake (1995): categorical aggregation; direct interpretation; patterns; and naturalistic generalizations.

The analytic technique chosen for this study was template style, which involved an open-ended codebook that underwent revision after encountering the text (Crabtree & Miller, 1992). Investigators using a template style generally organize their observations into categories or codes (Creswell, 1998). Basic categories were derived from the questions in the interview guides, and used to construct a set of preliminary codes. Basic categories derived from the major headings or questions of the interview guides included: dimensions, strengths, weaknesses, and experiences of telephone support.

A line-by-line review of the transcribed data was completed, applying the preliminary coding scheme. Key words that captured the essence were written in the right margins of each page, and were added to the coding scheme. The iterative process of coding, code development, and recoding continued until all the data were coded. Stake (1995) refers to this process as categorical aggregation. Categorical aggregation involves the search for examples from the data while searching for issue-relevant meaning (Stake). Interview data either supported or modified these preliminary codes (or categories). For example, interview data revealed that information and referral, and emotional support were aggregated under the preliminary category of “dimensions” of telephone support. Data from both the caregiver and provider interviews supported this preliminary code.

After coding the text with broad preliminary codes, refined sub-codes were derived from examples of the text. Referred to as direct interpretation (Stake, 1995), data were pulled apart and put back together again in more meaningful ways. This led to a further consolidation of the coding scheme. For example, the preliminary code of

“dimensions of telephone support,” was expanded to include a number of sub-codes such as: “acknowledgement, encouragement, reassurance, companionship”. The revised codebook was enhanced to include both preliminary and detailed sub-codes.

Eventually key features and patterns begin to surface from the revised codebooks, which is the third stage of data analysis and interpretation according to Stake (1995). A diagram was created to facilitate the generation and verification of relationships within the data, as suggested by Crabtree and Miller (1992). For example, the diagram facilitated an enhanced understanding of the relationship between the telephone support intervention and various outcomes of the caregiving experience. More specifically, it helped clarify how the intervention helps to minimize negative outcomes such as loneliness as it allows an immediate connection to someone who cares and can help (companionship), and fosters positive outcomes such as mastery and self-esteem with ongoing acknowledgement, encouragement, and reassurance (See Chapter 4, p.76 for diagram).

Data were coded and recoded repeatedly until information saturation was reached (no more new themes or patterns were established within the data). The data were then summarized to create generalizations; according to Stake (1995), naturalistic generalizations allow the readers of the research to learn from the case.

Challenges of Qualitative Inquiry with Caregivers

I began this qualitative case study with a bundle of energy and a high level of enthusiasm. I had a well-planned design, support from colleagues, and a desire to help all

dementia caregivers, – in particular, a very close relative of mine. However, as the study progressed, I began to encounter a variety of challenges. The obstacles related to both the process of qualitative inquiry (in general), and the caregiver population. I will speak to these challenges and the strategies I used to overcome them.

Qualitative Inquiry

Qualitative research is conducted when a topic needs to be explored and described in detail. According to Creswell (1998), this description can be enhanced when the researcher studies the participants in their natural setting, asks questions that are open-ended, encourages maximum input from the participants, and listens to the participants for as long as they are willing to contribute data conducive to the study. In my attempt to comply with some of these recommendations, I experienced a great deal of anxiety as I began to contact each participant to arrange the dates and locations of the interviews, and struggled with role conflict and investigator influence as I began to collect and analyze the data.

Contact Anxiety

One of the first challenges I faced in conducting this study was that of contact anxiety. I experienced feelings of uneasiness while scheduling and conducting the qualitative interviews. Johnson and Clarke (2003) describe this as contact anxiety. Several phone calls and date changes were required for three of the eight caregivers. This not only produced feelings of frustration, but also evoked great anxiety as the last thing

that I wanted to do was create additional burden for the caregivers involved. I struggled with questions such as, "How long shall I continue to try to arrange this interview? How many more calls shall I make?". For one participant, I left it up to the caregiver to call back when she was available to meet. There was no response after three weeks, so the responsibility of contact became mine again. This anxiety stemming from on-going attempts to contact some of the participants in this study definitely drained some of the enthusiasm and energy that I originally had for the study.

This contact anxiety was magnified by changes at the system level. Finding an under-researched area originally promoted enthusiasm, especially since initial reactions from others seemed favorable, and suggestions of funding and support had been offered. However, sometimes it is only when the research begins, that the real level of support (or lack of) becomes evident. Just prior to data collection, a new Director was hired at one of the organizations involved in the study, which hindered the recruitment of participants and decreased the amount of proposed funding. Alty and Rodham (1998) describe this as overestimating the level of support and interest. Despite feelings of frustration and disappointment, I overcame this obstacle and was able to maintain some enthusiasm for the study by focusing on those individuals who remained interested in the research. It was also helpful to have read the articles by Alty and Rodham and Johnson and Clarke (2003) who identified similar incidences related to investigators conducting sensitive qualitative research.

Investigator Influence

In qualitative inquiry, the investigator is often referred to as the research instrument. As Patton (1990) elaborates, “the human factor is the great strength and the fundamental weakness of qualitative inquiry and analysis” (p. 372). The investigator as the research instrument is challenged to minimize the influence of their own personal values, beliefs and previous knowledge on the data that they are collecting. I found it particularly challenging in this study to set aside my current values and beliefs about caregiving, especially since my current employment and personal philosophy revolve around providing assistance to others. For example, I believe that regardless of the sacrifices that have to be made when one decides to care for someone, it is a honourable duty that can be seen as an act of love, as a returned favour, or as a moral obligation. I also believe that there should be no restrictions on the amount of home care a caregiver receives, and that one of the goals of home care should be to maintain the caregiver and the person with dementia in the community for as long as they are able to manage. Home care services should be offered as a preventative measure, prior to the onset of caregiver burden, depression, or deteriorating caregiver health, instead of being offered as a “fix” to these situations.

Reflexivity is one way I was able to confront the challenge of minimizing the influence of my own personal beliefs and values on the data I collected and analyzed. I maintained research memos throughout the study. These memos were used to document any emotions or personal opinions I needed to “set aside” during and after the interviews and data analysis, in order to achieve maximum understanding of the experiences of the

participants in the study. Huberman and Miles (1994) suggest the need for detailed accounts and documentation (memos) for tracking and displaying the on-going, self-consciousness raising or “using a reflexive stance”. They argue that sharing the entire experience and insights more fully with readers makes a researcher more accountable and the research more credible (Huberman & Miles).

The research memo is an ideal strategy for identifying and incorporating personal perspectives into this study without compromising the research (Maxwell, 1960). Such memos should display the investigator’s mind processes, philosophical position, and the bases of all decisions made throughout the inquiry (Cutcliffe, 2003). This strategy was very helpful in that it made me aware of my existing opinions regarding caregiving, and how it was going to potentially influence the analysis and write-up of the research. By being aware of my strong feelings associated with caregiving, I was able to better understand why someone would refuse or withdraw from caregiving activities.

Consequently, I did not pass judgment on those who had decided to have their loved ones placed in a long term care facility, or had made arrangements for temporary respite admissions to a hospital or nursing home. I was able to better understand their decision process and what they must have been going through as a caregiver. This realization was crucial for the purposes of this research study, especially since I have never been a caregiver.

Role Conflict

Role conflict was another challenge I encountered, which occurred mainly as I was collecting the data in this qualitative study. In a study by Johnson and Clarke (2003), several researchers reported role conflict as being of major concern in qualitative research. Some of the issues that were of particular concern included: (a) researcher versus health care practitioner; (b) friend versus data collector; and (c) not being able to reciprocate (Johnson & Clarke).

Establishing trust and respect quickly with the participant is crucial in a qualitative interview in order to elicit personal and truthful responses. This can be challenging when the investigator is meeting with the participant only once and for a specific amount of time, and has the potential to impact the quality of the data collected. To overcome this obstacle, time was taken to speak with each participant briefly prior to the interview for the purpose of establishing some rapport, and principles of effective communication (ie., eye contact, posture, nodding) and active listening were employed throughout the interview session. This was quite similar to the process of conducting a health assessment. Initially, I had difficulty conducting the interview without giving advice about caregiver resources and activities, and commending the caregivers for their efforts. This was in part due to my natural behavior as a registered nurse, and as a nurturing individual.

After conducting the first four interviews with caregivers, I asked two other qualitative researchers to review the transcripts for me, for the purpose of providing feedback on interviewing techniques and to determine the need for additional data. At

this time, it was brought to my attention that I was fluctuating between the role of the researcher, case manager, and registered nurse. One example to illustrate this role conflict occurred during my second interview with a caregiver. I arrived at the house to find the caregiver crying in the doorway. The caregiver described how tough the morning had been in trying to get her husband ready in time for the bus to take him to the Adult Day Program. She informed me that for the second consecutive day, their home care worker had not shown up to help with her husband's personal care. I immediately switched to my role as case manager and proceeded to make a phone call to the Community Care Access Centre (CCAC) to report the occurrences. I also spoke with the caregiver about how the system works, what she was entitled to, and whom she should call if this were to occur again in the future. The situation eventually subsided and the interview began, however the caregiver continued to refer to my role as case manager, based on the actions that took place before the interview began.

In order to manage the role conflict, I referred to a few different strategies. One method that assisted me to overcome this challenge involved "playing one role at a time". After arriving, I would introduce myself and the study, collect the required data, before mentioning my other role as a case manager at a CCAC, and before giving advice and/or praising the caregivers for their efforts. This not only assisted with gathering pertinent data related to the interview questions, but also prevented a conflict between roles throughout the interview.

As a case manager working in an Ontario CCAC, one of my roles is to provide home care assistance for those in the community setting. However, it is also an

expectation of my role as a case manager to minimize service utilization and care-related costs. To some extent, I felt like I was betraying the caregivers. I am well aware that minimal support from the CCAC is available for the prevention of caregiver burden and distress, as current community case management practices most closely resemble a “problem-based” versus a preventative “strengths-based” approach (Sutherland, 2000). This ethical conflict between my role as a case manager and as a research investigator committed to assisting caregivers within the community caused me to feel moral distress. I experienced feelings of helplessness and powerlessness, and struggled with not being able to reciprocate or repay the participants for their time and energy.

Again, through written research memos and continuous evaluation of my responses and dynamics with each participant, I came to realize that I was not betraying the caregivers in any way by working as a case manager at a CCAC. In fact, it was this employment experience that made me aware of the weaknesses of the home care system, and that with the knowledge gained during my employment as a case manager, I have the power to inform others with my research, and ultimately assist those caring for loved ones in the community. To express my gratitude and reciprocate for the caregiver’s time and energy, I offered to send copies of the study’s findings. All of the caregivers responded that they would be interested in reading material to which they had contributed.

Qualitative Inquiry with Caregivers

The second source of challenges that I faced during this qualitative inquiry can best be described as challenges related to the lives of caregivers. A qualitative investigator must be patient and flexible when attempting to collect data from a caregiver. Because the investigator is asking the caregiver for a commitment of time, recall and perspectives on potentially personal or sensitive topics, it must be ensured that the location is suitable for the participant, and on a date/time that is also convenient for the participant.

Flexibility and Finding a Suitable Location for the Interview

This study was particularly challenging as it involved caregivers of persons with dementia, individuals who already have limited personal time and experience burden associated with attending to others. For the most part, interviews were conducted throughout south central Ontario, in the homes of the caregivers, at their request. This was somewhat challenging for me as I am not familiar with the area, and I struggled to find each location, in a variety of weather conditions, at different times within the day. At the time of data collection, I was holding three separate part-time jobs, and found it particularly arduous to be flexible. Although I eventually managed to accommodate each request, it was not without its difficulties and stresses.

The only interview that was conducted outside of the home environment took place at a local coffee shop. This was at the caregiver's request, which presented its own challenges for conducting a qualitative interview. First, this location was crowded and

noisy, and did not allow for taping of the interview. Even though notes were written throughout the interview, a great amount of data was lost as the interview was not audio-taped, and there was an absence of rich descriptive quotes from the participant.

Distraction was also a problem in this environment, which disrupted the flow of information, eliciting only quick, short answers. Due to the close proximity of others within the restaurant and the risk of being overheard, there was also the possibility that some information was not disclosed during the course of the interview.

Although I did not obtain the rich data that I had hoped to collect from this interview, I was still able to record a few key themes and quotes that I learned from that encounter. After the interview and as the caregiver and I were walking to our cars, I remember her thanking me. She was grateful to be “outside of the home”, as she had experienced a tough week caring for both her mother and an ailing daughter, and “really needed to get some fresh air”. Just moments before this final exchange, during the interview, this caregiver had described being “locked in” her house – unable to leave her mother alone inside, and trying to prevent her mother from escaping to the outside. It was at this moment that I realized the significance of being flexible with the caregiver population.

Flexibility and Finding a Convenient Time

Time is also a factor that requires flexibility on the part of the qualitative investigator – particularly in caregiving research. For example, the study was to initially include one-hour, face-to-face audio-taped interviews with each of the participants.

However, two of the caregivers recruited for the study specifically requested that the interview take place over the telephone, as this was more convenient. One asked that the time not extend over ten minutes, as she had to go out and run errands while the personal support worker was with her father. This request came after six previously scheduled interview times that had to be cancelled. This is a caregiving reality – caregivers of persons with dementia are unable to leave their loved one unattended. As this interview over the phone was unexpected, it was also not audio-taped. Again notes were taken, but details were missed and the interview was compromised due to the short amount of time allotted to answer 14 questions.

To prevent future loss of verbatim data during a telephone interview, equipment was borrowed to audio-tape a conversation over the telephone. Subsequently, the final caregiver also requested that the interview be conducted over the telephone as her house was in disarray and being renovated to support better care for her father. This interview was re-scheduled three times at the request of the caregiver, and the interview was conducted in two parts, at two different times (while the care recipient was napping). One of the main reasons for re-scheduling the interviews included a lack of assistance from either formal or informal supports, to allow the caregivers to take a break from their caregiving duties so that they could participate in the interviews. This highlighted another reality of being a caregiver in the community – inadequate home care support to assist caregivers, particularly those who have not yet “burnt out” or are experiencing a great amount of caregiving-related distress. Although it would have been helpful to observe the environmental context in which the caregiver was situated, for the most part,

the data collected during this interview were not compromised. However it certainly required patience and flexibility on my part, to collect interview data from these caregivers.

In contrast, some of the caregivers were so grateful to have someone listen to their stories that the interviews lasted longer than an hour, and frequently involved information that was off-topic. This required some creativity to refocus the interview so that the data collected would assist in answering the study questions. For example, during the course of this study, two caregivers took the opportunity to vent frustrations about home care assistance and physicians, and anger relating to the care provided at local nursing homes. In both situations, all concerns were acknowledged and an attempt was made to get the interview focused back on telephone support.

Asking Sensitive Questions

Conducting qualitative research with caregivers can be challenging in that it may include questions that relate to sensitive issues and personal information. Two of the caregivers interviewed in this study revealed that they had not expected to get upset during the interview, but did in fact begin to cry, and the amount of pain and distress they were experiencing was evident. In both experiences, frustration was primarily related to inadequacies of home care support.

In anticipation of the sensitive nature of the topic, I had attempted to deal with the potential discomfort or emotional pain associated with the study's questions by forewarning the participants of the content of the interview before it began. Not only was

this mentioned on the written consent form and described again before obtaining verbal consent, but the participants were also informed of their right to terminate, postpone, or withdraw from the interview and study at any time if they were not comfortable disclosing the required information. Acknowledging the potential impact that some of the questions may have on the caregivers and appearing “prepared” to deal with any emotions that may present, helps to establish the safe and comfortable environment required to elicit personal and emotional experiences. Fortunately with the two caregivers who were upset, they felt comfortable enough with the whole situation to continue with the interview. Afterwards, they informed me that they were grateful that someone was “listening to them”, and appreciated the opportunity to express their frustrations and emotions.

Giving Up Personal Time

Agreeing to participate in a qualitative research study also requires a commitment of time on the part of the caregiver. It was discovered throughout the course of this study that time is a major factor associated with caregiving. Constant supervision is required specifically for persons suffering with dementia, as there is a potential for wandering, a potential for self-harm/injury, and a potential for damage or destruction to their immediate environment. For example, because the bus was late to pick up the care recipient for a Day Program, the caregiver was unavailable to commit to the interview until her father had left the home. These caregivers are often only relieved of caregiving duties when a home care worker comes into the home or the care recipient attends a

program outside of the home. Additionally, home care assistance is unpredictable and caregiver support programs outside of the home present their own challenges for caregivers with regards to time. In another example, the home care worker did not show up on a scheduled date to relieve the caregiver of her duties, so the caregiver could not commit to the interview, and a new date/time had to be set.

More than half of the caregivers interviewed viewed “their personal time” as time not related to caregiving in any way. Once relieved of their caregiving duties, caregivers would use this time to run personal errands, visit with friends, attend personal medical and health-related appointments, and participate in activities that they enjoyed. Two caregivers specifically informed me that they did not want to “use this time” to talk or listen to anything related to caregiving. On these two occasions, interviews were scheduled while the person with dementia was napping and/or in the other room watching television. Personal time is rare and very valuable to caregivers of persons with dementia.

In summary, this study opened up several new avenues of learning. In addition to advancing my knowledge and skills related to the process of qualitative inquiry, I discovered the importance of acknowledging the overall impact of the qualitative interview process on the caregiver participant. By overcoming a variety of challenging situations, I was able to learn the significance of being flexible in finding a suitable interview location and date, recognizing the potential impact of the study’s sensitive questions, and respecting the time commitment required by the caregiver participants.

I was also impacted with a different set of challenges while collecting qualitative inquiry with the caregivers. I experienced role conflict and contact anxiety, and had to be aware of any potential influences on the collection or analysis of the research data. However, despite the trials and tribulations encountered while conducting this study, I was able to gain important and new insights that contributed to the existing knowledge of caregiver telephone support. Qualitative inquiry is crucial in order to understand an experience, and is a powerful source of information especially if we are to extend our understanding of the strengths and limitations of this support service, and build knowledge in the area of dementia care.

References

- Alty, A., & Rodham, K. (1998). The ouch! factor: Problems in conducting sensitive Research. *Qualitative Health Research*, 8, 275-282.
- Crabtree, B., & Miller, W. (1992). *Doing qualitative research*. Newbury Park, CA: Sage.
- Creswell, J. (1998). *Choosing among five traditions: Qualitative inquiry and research design*. Newbury Park, CA: Sage.
- Cutcliffe, J. (2003). Reconsidering reflexivity: Introducing the case for intellectual entrepreneurship. *Qualitative Health Research*, 13, 136-148.
- Finlay, L. (2002). "Outing" the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research*, 12, 531-545.
- Huberman, A., & Miles, M. (1994). Data management and analysis methods. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 428-434). Thousand Oaks, CA: Sage.
- Jarrett, N., Payne, S., & Wiles, R. (1999). Terminally ill patients' and lay carers' perceptions and experiences of community based services. *Journal of Advanced Nursing*, 29, 476-483.
- Johnson, B., & Clarke, J. (2003). Collecting sensitive data: The impact on researchers. *Qualitative Health Research*, 13, 421-434.
- Keen, J., & Packwood, T. (1996). Case study evaluations. In N. Mays & C. Pope (Eds.), *Qualitative research in healthcare*. London: B.M.J. Publishing Group.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Maxwell, J. (1960). *Qualitative research design: An interactive approach*. Thousand Oaks, CA: Sage.
- Miles, M., & Huberman, A. (1994). *Qualitative data analysis: A source book of new methods* (2nd Ed.). Thousand Oaks, CA: Sage.
- Noonan, A., & Tennstedt, S. (1997). Meaning in caregiving and its contribution to caregiver well-being. *The Gerontologist*, 37, 785-794.
- Patton, M. (1990). *Qualitative evaluation and research methods*. Newbury Park, CA: Sage.

- Pearlin, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583-594.
- Plant, H. (1996). Research interviewing. *Palliative Medicine*, 10, 339-341.
- Stake, R. (1994). Case Studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research*. Thousand Oaks, CA: Sage.
- Stake, R. (1995). *The art of case study research*. Thousand Oaks, CA: Sage.
- Sutherland, C. (2000). Community-based nurse case management: The lived experience. *The Western Journal of Graduate Research*, 9(1), 66-74.

CHAPTER FOUR

Seeking to Understand Telephone Support For Dementia Caregivers:

A Qualitative Case Study

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A Paper Included in the Sandwich Thesis
Submitted to the School of Graduate Studies
In Partial Fulfillment of the Requirements
For the Degree Doctor of Philosophy

McMaster University

Hamilton, Ontario

Sept. 7, 2004

The growing elderly population, budget constraints and technological advances in North America have led to reduced inpatient hospital stays, a shortage of available nursing home beds, and an emphasis on post-acute services in home care (Merlis, 2000). This shift in care to the community has contributed to an increased level of burden on informal support networks of family and friends (Grunfeld, Glossop, McDowell, & Danbrook, 1997). More specifically, this shift in care has placed increased demands on families trying to cope with the changing needs associated with caring for a person with progressive dementia at home, contributing to increased levels of physical, psychosocial and financial burden (Durand, Krueger, Chambers, & Grek, 1995).

Telephone support is one method of delivering information, education and psychosocial support to informal caregivers of persons with dementia, and has been proposed as a feasible alternative means of meeting the identified needs of caregivers (Ploeg, Biehler, Willison, Hutchison, & Blythe, 2001; Short & Saindon, 1998). In addition, recent research has demonstrated that caregivers express a preference for telephone support as a means to meet their needs (Colantonio, Cohen, & Corlett, 1998; Colantonio, Kositsky, Cohen, & Vernich, 2001). However, there has been very little published research describing the intervention of telephone support and its impact on the caregiving experience.

This paper begins with a brief overview of the background literature and methods involved in this qualitative case study of the intervention of telephone support. The principal focus of this paper is on the findings generated from the subjective experiences of both caregivers and providers of this form of support. This is a unique contribution to

the existing literature as it is the only qualitative study to date to focus on one-to-one (professional to caregiver) telephone support for family caregivers of persons with dementia.

Background

The literature reviewed for this study includes research related to caregiver support interventions and telephone support interventions. Nine systematic reviews were retrieved that focused on multiple interventions for caregivers (respite, support groups, counselling and educational sessions) (Acton & Kang, 2001; Bourgeois, Schulz, & Burgio, 1996; Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Knight, Lutzky, & Macofsky-Urban, 1993; Pusey & Richards, 2001; Roberts et al., 2000; Schulz et al., 2002; Sorenson, Pinquart, & Duberstein, 2002; Yin, Zhou, & Bashford, 2002). Overall findings from the literature on caregiver interventions reveal that they have little or no effect on caregiver burden, and that several barriers to these types of interventions exist including care receiver resistance, reluctance of the caregiver to accept the intervention, hassles for the caregiver, concerns over the quality of care, and concerns over finances (Wehtje Winslow, 2003). None of these systematic reviews focused specifically on telephone support.

Authors of recent caregiving literature stress the need to acknowledge and measure the negative effects of caregiving (ie., burden and depression), as well as the positive effects on the caregiver (Cohen, Colantonio, & Vernich, 2002; Kramer, 1997). Recent research demonstrates that interventions have a larger impact on a caregiver's

knowledge and ability (or levels of mastery) than on negative levels of burden and depression. Therefore, existing and future caregiver support interventions should continue to acknowledge and foster a caregiver's abilities and not just attempt to "alleviate or eliminate" the negative effects associated with the caregiving experience. This is consistent with current knowledge that has revealed that quality caregiving can coexist with caregiver burden, and that given the chronic nature of older people's health conditions, caregiving burden may not be readily reducible (Greenberger & Litwin, 2003).

Only 13 primary studies of telephone support interventions for informal caregivers were found, 12 of which were quantitative in nature. Six studies were randomized controlled trials (Coyne, Potenza, & Broken Nose, 1995; Gitlin et al., 2003; Goodman & Pynoos, 1990; Grant, Elliot, Weaver, Bartolucci, & Newman Giger, 2002; Hartke & King, 2003; Mahoney, Tarlow, & Jones, 2003), one was a quasi-experimental design (Brown et al., 1999), two were studies using before/after designs (Davis, 1998; Strawn & Hester, 1998), and three were descriptive studies (Coyne, 1991; Silverstein, Kennedy, & McCormick, 1993; Skipwith, 1994). Although the literature suggests that telephone support can positively affect both the physical and psychological health of caregivers of persons with dementia, it is difficult to confirm this finding from the individual research studies for two reasons. First, only two of the five strongest studies reviewed focused on caregivers of persons with a dementia (Gitlin et al., Mahoney et al.), and these studies investigated the use of either a computer-mediated interactive voice response system, or used telephone support as a control intervention.

Second, the only qualitative study that has been completed to date focuses on telephone support groups for informal caregivers of men with hemophilia and HIV/AIDS (Stewart et al., 2001). There remains a lack of qualitative research exploring the intervention of telephone support for family caregivers, specifically for caregivers of persons with dementia. This is crucial, as research evidence has demonstrated the greater demands faced by caregivers of persons with dementia when compared with caregivers of persons with other chronic illnesses (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999).

Finally, the reviewed literature failed to answer several important questions. What are the dimensions of the telephone support intervention? What are the experiences of caregivers who receive telephone support, and professionals who provide the service?

Methods

Qualitative inquiry is the method of choice for this study as attention is paid to the social context in which events occur and have meaning, and there is an emphasis on understanding the social world from the point of view of those who participate in it (Creswell, 1998). The purpose of this study was to acquire an enhanced understanding of telephone support by exploring the experiences of dementia caregivers with this intervention, and the experiences of providers with this service. The following questions formed the basis of the study:

- 1) What are the dimensions of the telephone support intervention?
- 2) What are the experiences of caregivers of persons with dementia who receive telephone support?

- 3) What are the experiences of telephone support providers who provide telephone support to caregivers of persons with dementia?

A qualitative case study design was chosen to guide the process of data collection and analysis. Following Stake's (1995) recommendations, this approach was chosen to capture the complexity of the intervention of telephone support. The case was bounded by geographical location (south central Ontario), and organization (telephone support provided by either the Alzheimer Society or a community agency that offers an Alzheimer Day Program). It was also bounded by time (receipt of telephone support within the last year), by provider (delivered by a health professional), and by the recipient of support (caregivers of persons aged 50 years or over with dementia).

Approval was received from the Faculty of Health Sciences, Research Ethics Board (R.E.B), prior to conducting this study. Participants were then recruited from either the Alzheimer Society or from the involved community agency, as these two organizations varied in the telephone support offered. One agency offered telephone support that was confidential and caregiver-initiated, and the other organization offered telephone support as follow-up to their other support programs and which could be initiated by either caregiver or telephone support provider.

Data Collection

Two sources of data were collected: (1) documentation of contextual data, and (2) interview data. Contextual data included researcher field notes and memos, demographic details regarding the participants and agencies, and information from a contact summary

sheet. Interview data included audio-taped, face-to-face or telephone interviews with caregivers and telephone support providers, including a former Executive Director of one of the two organizations who founded the Telephone Support Program as well as provided this form of support. Criterion and convenience sampling strategies were used to select the participants.

A total of 12 interviews were conducted: eight with caregivers, and four with telephone support providers. Half of the questions in the interview guide inquired about their experiences (caregiving or providing telephone support), while the other half focused specifically on the strengths and weaknesses of the telephone support intervention. Notes were taken during the interviews, and all but two of the interviews were audio-taped. To assist with the organization of thoughts and key themes, observation details of each participant and setting were recorded after each interview using a contact summary form devised by Miles and Huberman (1994).

With previous experience as a community nurse and current experience as a community case manager, the investigator was well aware of the previous knowledge, values and beliefs that she was bringing into the research. Various procedures were incorporated into the research process to help “validate” the collected data and ensure the credibility and trustworthiness of the research findings. This study allowed for two sources of triangulation to be used: data triangulation and investigator triangulation. Other methods of validation that were employed in this study included member checking, and the use of an audit trail and research memos. Finally, rich descriptions of the context of each caregiver situation and experience were incorporated into the analysis of the data

and described in the narrative of this study, for the purpose of ensuring that the findings are transferable to other settings and populations (Lincoln & Guba, 1985; Stake, 1995). A checklist proposed by Stake (1995) was also referred to while writing up the narrative portion of this study to ensure the overall quality of the case study report (See Appendix N for the checklist).

Data Analysis

Data analysis began while the transcripts of each interview were being “cleaned” or checked with the audio-tapes for the purpose of verifying the wording and content. As proposed by Stake (1995), the process of data analysis included categorical aggregation, direct interpretation, patterns, and naturalistic generalizations. To start, a preliminary set of codes were derived from the interview guides, and were based on the four central research questions of the study. For example, this codebook was categorized according to the dimensions of telephone support and experiences of both caregiver and provider.

A line-by-line review of the transcribed data was completed, applying the preliminary coding scheme. Key words that captured the essence were written in the right margins of each page, and were added to the coding scheme. The iterative process of coding, code development, and recoding continued until all the data were coded. Stake (1995) refers to this process as categorical aggregation. Afterwards, these new codes were “clustered” together and listed according to the preliminary categories, creating an open codebook. For example, information, referral, and emotional support were some of

the codes that were aggregated under the preliminary category of “dimensions” of telephone support.

Direct interpretation involves looking at examples and drawing meaning from them. This process involves pulling the data apart and putting them back together again in more meaningful ways, eventually leading to a revised codebook (Stake, 1995). After reviewing and pulling apart the segments of text under the category of “dimensions of telephone support”, the code of “emotional support” was expanded to include sub-codes of “acknowledgement, encouragement, and reassurance”. The revised codebook was enhanced to include both preliminary and detailed sub-codes (See Table 1 for the first page of one of the codebooks).

Eventually key features and patterns begin to surface from the revised codebooks, providing a better understanding of the intervention of telephone support. A diagram was created to assist with the generation and verification of relationships within the data (Figure 1). The diagram clarified the relationship between the telephone support intervention and various outcomes of the caregiving experience. More specifically, it demonstrated how the intervention helps to minimize negative outcomes such as loneliness as it allows an immediate connection to someone who cares and can help (companionship), and fosters positive outcomes such as mastery and self-esteem (with on-going acknowledgement, encouragement, and reassurance).

Table 1 First Page of Codebook #2 (Open coding)

Telephone Support Intervention (Caregiver)		TSC	3.0
TS:	Type Received	TSC-T	3.1
TS:	Information & Referral	TSC-Ti	3.11
TS:	Acknowledgement; validation	TSC-Tr	3.12
TS:	Behavior management; advice	TSC-Tp	3.13
TS:	Encouragement	TSC-Ts	3.14
TS:	Companionship	TSC-To	3.15
TS:	Emotional Support	TSC-Ta	3.16
TS:	Provider Initiated	TSC-Tt	3.17
TS:	Caregiver Initiated	TSC-Tc	3.18
TS:	Need for more help	TSC-Tn	3.19
TS:	Strengths	TSC-S	3.2
TS:	Someone always there (security)	TSC-St	3.21
TS:	Someone who will listen	TSC-Sl	3.22
TS:	Someone who knows your situation	TSC-Sk	3.23
TS:	Support after death of loved one	TSC-Su	3.24
TS:	Reassurance	TSC-Sr	3.25
TS:	Someone who can help; arrange help	TSC-Sh	3.26
TS:	Easy; convenience; flexible	TSC-Sc	3.27
TS:	Provide updates/follow-up	TSC-Sp	3.28
TS:	Assistance with coping	TSC-Sa	3.29
TS:	Limitations	TSC-L	3.3
TS:	Hours of availability	TSC-Lh	3.31
TS:	Suggestions	TSC-U	3.4
TS:	Maintain flex. (caregiving changes)	TSC-Um	3.41
TS:	Start up overnight respite	TSC-Us	3.42
TS:	Support groups	TSC-Uu	3.43
TS:	During ADP	TSC-Uu- <i>d</i>	3.431
TS:	More often (summer)	TSC-Um- <i>m</i>	3.432
TS:	Ed. sessions/resources more avail.	TSC-Ue	3.44
TS:	Restart info. evening @ St. Joe's	TSC-Ur	3.45
TS:	Stressful coordinating	TSC-Uc	3.46
TS:	24 hours	TSC-Ut	3.47
TS:	Know your provider	TSC-Uk	3.48
TS:	Providers should have lots of exp.	TSC-Up	3.49
TS:	Recommend?	TSC-R	3.5
TS:	Yes - along with rest of program	TSC-Ry	3.51
TS:	Yes - good "in-betweeners"	TSC-Rg	3.52
TS:	Impact	TSC-I	3.6
TS:	Whole package "lottery ticket"	TSC-Iw	3.61

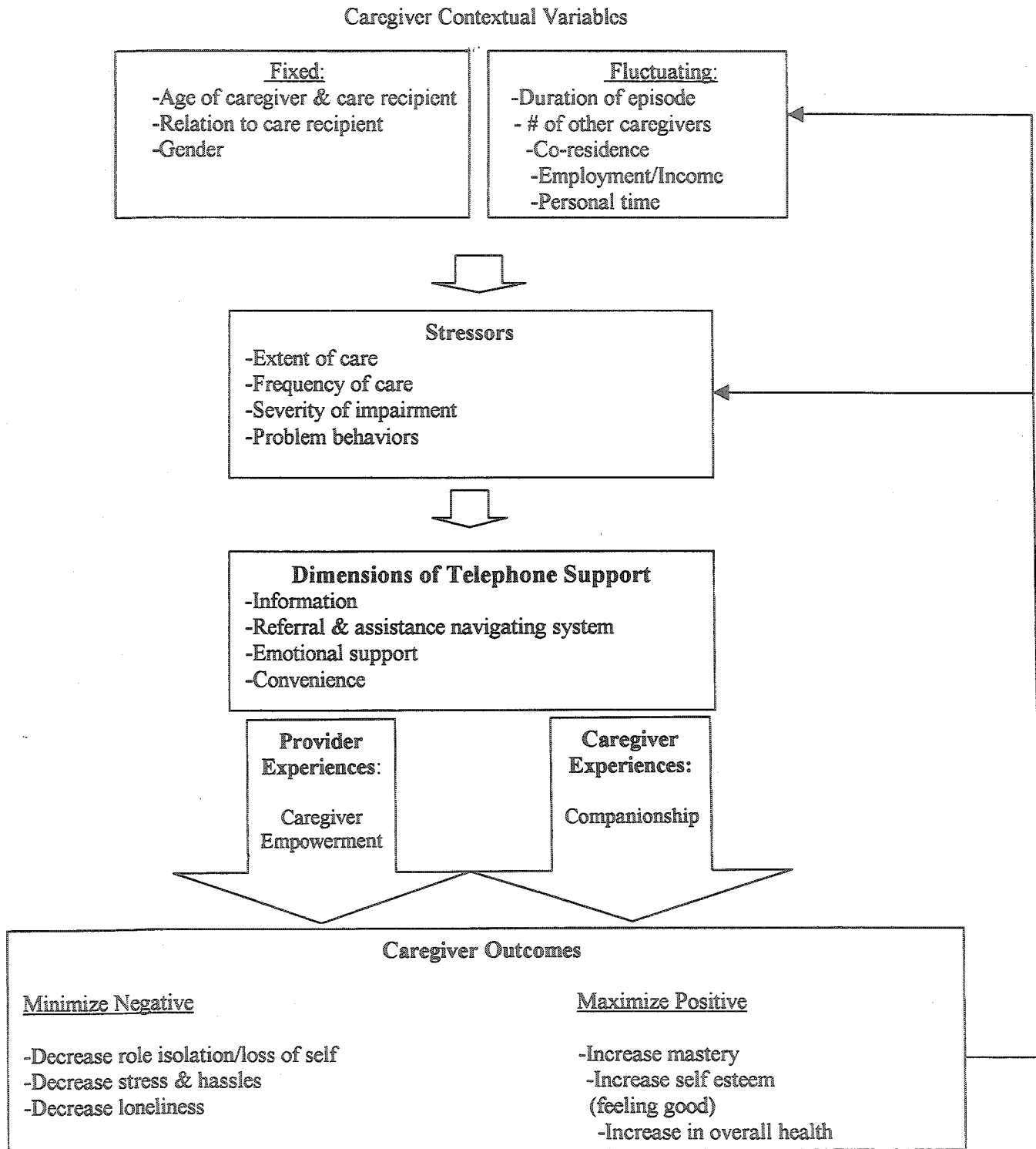


Figure 1. Telephone support and the dementia caregiver stress process.

Data were read and sorted repeatedly until information saturation was reached (no more new themes or patterns were established within the data). Once the data were organized and coded for the final time, the goal was to summarize the data and create naturalistic generalizations that people can use to learn from this case (Stake, 1995).

Findings

The aim of this case study was to understand the intervention of telephone support as provided by professionals to caregivers of persons with dementia. The study findings are described in four sections: (a) the context of the study, which includes the dimensions of the caregiving experience, and the telephone support services and providers; (b) the dimensions of the telephone support intervention; (c) dementia caregiver experiences with telephone support; and (d) provider experiences with telephone support.

The Context

Dimensions of the Caregiving Experience

Demographic data were collected at the start of each caregiver interview. This data provided important details related to the context of each individual caregiving situation. The data revealed that all participants were female, and six of the eight caregivers were between the ages of 50-60 years old. More than half of the caregivers were children of the person with dementia, and lived in the same house as the care

recipient. These caregivers also stated that they were unemployed as a result of their decision to provide care for their loved one.

Caregivers were at various stages of caregiving. Half of the participants had been providing care for three to five years, while two caregivers had been providing care for more than five years. This finding demonstrates the ongoing commitment involved when caring for a person with dementia. Three caregivers were in the process of finding a long-term care bed at a nursing home for their loved ones, one had just moved the care recipient to a nursing home facility, and one had recently experienced the death of the care recipient (See Table 2 for characteristics of the caregivers and care receivers).

The findings of this study revealed four dimensions of the caregiving experience: (a) “no life” and role isolation, (b) “locked in” and lonely, (c) deteriorating physical and mental health, and (d) feeling good about caregiving.

(a) *“No life” and role isolation.* The commitment of caring for someone with dementia can be overwhelming, and it is not uncommon for caregivers to feel that it becomes their only role and purpose in life. Since caring for someone with dementia is an on-going commitment, it was not surprising that some of the caregivers alluded to having “no life”, as they made several personal sacrifices in order to fulfill their role as the primary caregiver. The following quote provides an example of this feeling.

It's just every day, it's the same thing, I've got no life and, I don't know what it's like to work anymore, I don't even know if I could do that anymore. I just worked a little bit, started to work before I came here. To tell you the truth, I did not know what I was getting into (Caregiver #5).

Table 2 Description of Caregivers and Care Receivers

Caregivers (n=8)

Care Recipients (n=7)

Characteristic	Number	Characteristic	Number
Age:		Age:	
a)50-60 years	6	a)70-80 years	1
b)60-80 years	2	b)80-90 years	6
Gender:		Gender:	
a)Male	0	a)Male	4
b)Female	8	b)Female	3
Relationship to care receiver:		Severity of cognitive impairment: (as per caregiver)	
a)Spouse	3	a)Mild	1
b)Child	5	b)Moderate	3
		c)Severe	3
Living Arrangement:		Other diagnoses:	
a)Same home as care receiver	5	a)Physical Impairment	4
b)Other	3	b)Incontinence	4
		c)Arthritis	7
Unemployment (as result of caregiving)	5	Main safety concerns:	
		a)Wandering	7
		b)Falls	7
		c)Abusive behaviours	2
Duration of caregiving:		Nursing Home Placement Status:	
a)<1year	1	a)Waiting	2
b)1-3 years	1	b)Placed	2
c)3-5 years	4	c)Assessment in near future	1
d)>5 years	2	d)Other	2

Note: 1 care receiver was deceased prior to the interview with caregiver

(b) *Locked in and lonely.* Caregivers described a life that was “locked in,” requiring them to supervise 24 hours per day as they strived to protect their loved ones from wandering outside of the house, or injuring themselves.

He needs twenty-four hour supervision because ... He gets lost in the house. He thinks there are rooms where there aren't any. Sometimes he thinks people have been here, and nobody has been here ... he has tunnel vision too. Like he can be in a room, and if he walked by that room, he doesn't see you. Or, you know, if he was left in the house alone, as an open house, I'd be afraid of him falling down the stairs. You know, getting a sharp knife. He doesn't have a knife at the table because I'm afraid he'd cut himself. So he has a fork and a spoon ... If he decided he was going to go out for a walk, he just ... for one thing, he'd walk out in traffic. He has no fear. He'd have no fear of that. He'd have no fear of the traffic (Caregiver #1).

My life has been geared towards my mom and her Alzheimer disease. I have put signs and reminders around the house for mom; have made the house a locked house – with all the windows and doors bolted shut as mom has wandered outside and become lost. She's locked in, but now so am I (Caregiver #3).

(c) *Deteriorating physical and mental health.* Another dimension of the experience of caregiving was deteriorating health. Participants described the negative consequences of caregiving on both their physical and mental health.

I'm exhausted; my physical health has gotten worse; fibromyalgia and chronic fatigue syndrome has flared up more often (Caregiver #3).

This is the difficult part about it ... I'm the enemy all the time ... And uh, he's always putting me down and he's always right and I'm always wrong ... So this is a challenge and, and I feel so sorry for him you know, because he's losing his marbles and, yet he doesn't think he is, he thinks I'm the one that has the problem (Caregiver #8).

One caregiver even described her thoughts of suicide in response to the demands of caregiving.

I, I never got upset. I never cried. I had been planning before to do something about the two of us. I did. I had it all planned. He was so sweet. In between he didn't know who the hell I was but, but he was, and he was beautiful too, and uh, I don't know, I, I just, I remember exactly what I did I, I had these pills for him to, supposed to calm him down... I took the whole bottle. And thought, had a cup of tea, thought this is it. Least I won't hurt if I have to put him in (a nursing home) ... Just so I didn't have to face it anymore ... I know it was a cop out, but ... He didn't know anymore, he just was trapped and uh, I thought, I can't, I can't let

him hit me anymore ... it took me another year to get over that guilt... (Caregiver #6).

(d) Feeling good about caregiving. Despite all of the hardships and stresses associated with caring for a person with dementia, some positive aspects of the caregiving experiences were also highlighted in the caregiver interviews. Caregivers talked about the rewards associated with caring for their loved one, and “feeling good” about themselves, as revealed in the following quotations.

Well, sometimes I feel like I'm doing something good you know, and I do get a little bit of pride in that I'm helping somebody function and, that's sometimes yeah, it just makes me feel okay that I'm doing something good for someone. Taking care of somebody who can't take care of themselves and ... sometimes it makes me feel good when I'm making appointments and stuff ... just basically that...just taking care of her needs (Caregiver #5).

Good because I, mostly because I can have them sweet moments. Do you know what I mean? They weren't always there but they were precious. I have to be truthful ... I always felt good about when I could make things happen (Caregiver #6).

I feel good because I know that I am doing all that I can do for him (Caregiver #2).

One caregiver talked about the importance of giving the best possible care:

Well you're looking after your loved one and giving them the best care that you possibly can ... And hoping that, hoping that it is the best that you're doing and um, loving them and listening to them, giving them a big hug when they need it. And they do need it a lot (Caregiver #8).

The Case

Telephone Support Services and the Providers

All four telephone support providers interviewed in this study were female, and ages ranged from 30-65 years. They were recruited from either of two organizations in

south central Ontario that offered telephone support to caregivers of persons with dementia.

The first organization offered confidential telephone support, eight hours per day, which was strictly initiated by the caregivers. Generally, if it were only information that was required by the caregiver, the secretary would provide this service and refer the caregiver to community supports as necessary. If emotional support was needed the calls would be transferred to either of two telephone support providers. Providers in this agency offered counselling and emotional support, as well as information and referral to other supports available within their organization (ie., education sessions, literary and video resources), or to formal supports within the community. It was not in their mandate to perform follow-up calls to the caregivers. The two telephone support providers at this organization had combined gerontology degrees, with either psychology or social science as their secondary degrees. The retired telephone support provider and previous Executive Director had a graduate degree in nursing. Two of the three providers had personal experience as a caregiver (See Table 3 for characteristics of sources of telephone support).

The second organization offered a caregiver support program which included an Adult Day Program, support groups, educational sessions, and telephone support. The telephone support differed from the first organization in that a face-to-face assessment was conducted prior to the involvement in the program. After the assessment, caregivers were free to access any of the services provided. Follow-up calls were made on a regular basis to update caregivers of new services being offered, and to inform them of any

changes or concerns related to the care recipient, as the providers were familiar with each caregiver/care receiver situation. Frequency of telephone support was based on need, and was both provider and caregiver-initiated. All telephone support providers in this agency had nursing backgrounds, and the lone provider interviewed from this organization had previous experience as a caregiver (See Table 4 for characteristics of providers).

What are the Dimensions of the Telephone Support Intervention?

The study findings revealed four main dimensions of the intervention of telephone support. Telephone support meets: (a) the information and educational needs of caregivers; (b) the need for referral to other sources of supports within the community, and/or assistance required to navigate through the system; (c) the need for emotional support; and (d) the need for caregiver support that is convenient and hassle-free.

(a) Telephone Support Meets the Need for Information and Education

Both caregivers and providers described the intervention of telephone support as a source of information and educational advice, tailored to each individual caregiving situation. One caregiver gave a specific example of some of the information and advice she received while accessing telephone support:

My husband had very bad problems when he had constipation. He didn't go for ten days. So I called for advice ... and she was going to send me a recipe for mixing All Bran and applesauce and prune juice ... and then he went, so I called her back to thank her for being concerned (Caregiver #2).

A telephone support provider described some of the information she provided to the caregivers.

Table 3 **Characteristics of Sources of Telephone Support**

	Alzheimer Society	Community Agency
Type of Support	- information & advice - referral - emotional support	- information & advice - referral - emotional support
Availability	- business hours -8 hours/day -Monday-Friday	- business hours -8 hours/day -Monday-Friday
Anonymity	- yes	- no - face-to-face meeting beforehand
Follow-Up by Provider	- no	- yes (calls made as needed)
Providers	- health professionals with dementia training	- registered nurses with dementia training

Table 4: **Characteristics of Telephone Support Providers (n=4)**

Ages	30-65 years
Gender -Female	4
Profession -Registered Nurse (public health or community experience)	2
-Gerontology Degree (with a minor in psychology or sociology)	2
Years of Telephone Support Experience	3-15 years
Previous Experience as Caregiver	3

Well, most of the people who phone in here, I would say, are really looking for information. Many people are information seeking ... And then, you know, I can send some stuff out. Or if they have specific questions, I can answer them ... Or they'll say: "My parents are having difficulty. Are there any services out there? How do we get in-home care?" I then tell them about the CCAC and what they do ... And then I tell them what our role is and what we do, which I think is more of an educational and support service really (Provider #1).

Caregivers also revealed their need for, or receipt of educational advice, strategies or "tools" to effectively manage and cope with problematic situations.

I call them sometimes when the Home Care doesn't show up and I don't know what to do (Caregiver #2).

So I would call ... can you give me some ... suggestions or something on how to cope with this ... and they're very good ... I find that helpful (Caregiver #5).

I wanted to make it better. I knew I could. I could do it. Just show me the tools ... I would be more content with myself (Caregiver #7).

One caregiver described an incident that involved immediate advice and strategy, offered through telephone support, in order to avoid an exacerbation of abusive behaviours by a person with dementia.

... they told me ... there is no point in arguing because he was always right. Always right. You know uh, for instance, he was putting both legs in his pant leg - one pant leg. Now he's very frustrated and he's becoming very abusive. The way to handle that I found was oh, to say ... please don't be mad at me, and he'd say, I won't be mad at you, and I'd take them away and straighten them out (Caregiver #7).

A provider described her role as providing emotional support, information and ideas to help the caregivers cope.

... emotional sort of stuff; you know, like when they're not able to cope. They don't know what to do anymore. And that's when we sort of ... I discuss with them ways that they might feel a little bit better, either through having time to themselves or using family and friends as a support, if they offer it. Certainly our support groups and that sort of thing (Provider #1).

(b) Telephone Support Meets the Need for Referral and Assistance to Navigate Through the System

Participants in this study described how telephone support helps caregivers to “navigate” through the complex system of community supports and programs.

Caregivers described how telephone support assisted them with making linkages within the system:

Well, if you need some reassuring, or advice or, some direction ... like they have really kept me in tune with all these different ... I never knew anything before, like Alzheimer's Society and ... the sites to go on the internet ... I never knew anything about the VON or CCAC or, or occupational therapy ... (Caregiver #5).

Actually it's the whole package that has helped me; right from my first phone call to (Telephone Support Provider's name). That phone call ... was just like somebody handing me a lottery ticket. You need the whole thing to survive this (multiple caregiver programs and supports). And I don't mean survive it like it's hell, {laughs} but I mean survive it to the point where you're comfortable living your life and you know ... you know in the back of your mind, no matter what happens, there's somebody else out there that can help you (Caregiver #1).

A providers described how she helped caregivers navigate the system and how telephone support was the “link”.

... and then I sort of direct them through the system really. I tell them how to sort of navigate through the system (Provider #1).

And I think the telephone support service could be the one that follows them through (the caregiving experience) because it's easy to access for the caregivers when times are just very activity intensive ... and not to get lost ... and through the telephone ... the telephone support service could be the link, the thread (Provider #1).

(c) Telephone Support Meets the Need for Emotional Support

Caregivers and providers identified the provision of emotional support as another key dimension of telephone support. They described the comfort of knowing that

someone is out there who will listen to them, acknowledge their efforts, and provide encouragement and reassurance,

There's somebody out there that will help you, whether you need someone to take Dad, whether you need some time for yourself, no matter what. There's somebody out there ... someone who understands ... and that's so important (Caregiver #1).

A provider talked about her role of listening and being there for the caregivers.

And I think a lot of people call and they just want someone to hear them and to know that they're not alone, you know, in those experiences (Provider #3).

(d) Telephone Support is a Convenient Way to Meet Caregiver Needs

Caregivers and providers recognized that the convenience of telephone support was an important dimension of this intervention. Caregivers could remain in their homes without having to leave the care recipient, while they accessed this service.

Well, because you can pick it (the telephone) up anytime, you don't have to go out, you don't have to leave the house, you don't have to get your mom all dressed ... When I need somebody, you know, they're there when you pick up the phone (Caregiver # 5).

Well, I think it offers a way for them to make that contact without leaving their home, because a lot of them just can't get out (Provider #3).

... it's a very comfortable situation because the caregiver can, from their own home, seek help. And they can be comfortable with the use of the telephone. They don't need to search for new supports for all of the new situations and concerns that come up (Provider #1).

A caregiver described one of the hassles involved with the specific dates and times of a caregiver support educational session.

They have this thing (educational session) on Wednesdays from 10 until 12 ... I called her about that. Um, they were booked up. They only have I think, nine people ... they have it also on Tuesdays, but I couldn't go on Tuesdays (Caregiver #8).

Also identified was the need for caregivers to receive support throughout the caregiving experience, even after the care recipient has been placed in a long-term care facility.

For dementia, it can go on for years, and you go through the different stages, and it isn't over until it's over... Caregivers undergo a number of transitions – from acute care to the home, from home to long-term care, to maybe special care. And it's during those transitions that people often get lost. So even when the person is placed in a long-term care facility, the caregiver has needs; sometimes more (Provider #1).

This need for on-going support is depicted in the following quotation. A caregiver counseling service was ended as soon as the care recipient was placed in a nursing home. The caregiver's continuing need for support was met by the telephone support service.

It was my counselor. ... I, I couldn't believe but that was the way things were set up. I thought, I need her now... (they stopped the service when her spouse was placed in nursing home) ... I was a basket case ... but [the telephone support provider] picked up the pieces after, you know what I mean? (Caregiver #7).

The findings from this study also revealed two caregiver needs that were not being met by current telephone support services: (a) the need for increased hours of availability, and (b) the need for a multi-lingual service.

(a) The Need for Increased Hours of Availability

All of the caregivers interviewed identified the need for telephone support to be offered beyond the 8-hour workday, especially during the final stages of the illness. Four of the eight caregivers described the need for a 24-hour service. The following quotations describe why extended availability of the telephone support intervention might be beneficial to caregivers.

... The time they're available, 'cause what if you get in trouble from eight (pm) to five (am). Oh well, it'd be nice to get maybe a hold of somebody 24 hours if there was an accident or ... one time, she (her mother) fell a while back and, she was in bed and I was really tired and I would've just like to have been able to get somebody on the phone and ask them some questions ... like what I should do next (Caregiver#2).

I think it's wonderful, I really do. I, I don't know if it would be necessary to have a 24 hours service... Um, but then, you know I don't know what's, well I do sort of know what stage of the Alzheimer's we're in now um, but I, I know it's going to get worse and as it gets worse, I may feel the need to have somebody there, more than I do just at the moment (Caregiver #8).

Similarly, the providers agreed that extended evening hours might be helpful in meeting the needs of dementia caregivers. The following quotation provides support for the need of such extended availability.

Well, you know, I'm sure for the caregiver it would be great if we were available in the evening ... I don't know how feasible that would be. We do have voice mail, but they'll just be able to leave a message. And I do ... you know, when I come in the morning, there are usually a couple of messages at least ... A lot of people do call after four-thirty ... Now they're mainly calls looking for information ... but some also for counselling (Provider #3).

(b) The Need for a Multi-lingual Service

The providers interviewed in this study spoke English only. One provider cited language barriers as a limitation of the current telephone support intervention, and the inability to meet the needs of caregivers whose native tongue is other than English.

Limitations. Okay. Language barriers. That is major because we have several clients that have trouble with the English language. I would not attempt... I mean it's hard enough to find out what the problem is, let alone to try and have a discussion (Provider #2).

What are the Experiences of Caregivers Who Receive Telephone Support?

Companionship

The major theme of caregiver experiences with telephone support related to a sense of “companionship and connection”. Caregivers talked about having a “lifeline”, and someone at the other end of the telephone.

Well if you're not able to get in, you need that phone. I mean ... it's as good as a meeting. Because maybe the meetings better for the, the counsellor, but for the person that's calling, you have a life line. You have somebody to touch with ... I know she's there and I can phone her ... And it's a, a security (Caregiver #7).

I mean it is so great, they really are. And uh, it's nice - better than winging it on your own. To have somebody on the end of the telephone when you have a problem (Caregiver #5).

Caregivers expressed a preference to speak with someone who was aware of their situation, specifically someone who knew the care recipient and his/her behaviors. One caregiver whose father attended the Adult Day Program and who had met with the provider face-to-face, described her preference for speaking with someone who was aware of her situation, and knew the caregiver's father.

There's always somebody there. There's an ear at the other end of that phone. Like the day (the telephone support provider) phoned here and I was going down to get the mop and the bucket 'cause dad couldn't find the bathroom ... And she goes: "Oh, I'm so sorry I called right now". I said: "Oh no, no. This is good. This is good. It's an excuse not to have to go back to the mess". There's a voice at the other end. And like I said: She called here and it was perfect timing 'cause I was just ready to tear my hair out; I was so frustrated. And, you know, she was an ear so you could vent. You put a face to the name and you know them and they know you and they know Dad. So they know what you're talking about. If you're talking to someone who doesn't know you, you don't know them, they don't know Dad, how can anybody give you advice? If you're speaking strictly people with dementia, there's so many different forms of it and so many different degrees of it, that how can you possibly give someone advice about something

that you don't even know the situation? I don't understand how they can do that. I think you have to know the person involved. Otherwise I don't think you can actually ... I mean blanket information is okay, but I don't think you can actually give good help or information ... if you don't know the situation or the person (Caregiver #1).

What are the Experiences of Telephone Support Providers?

The findings of the study revealed two themes related to provider experiences with telephone support: (a) helplessness and frustration, and (b) empowering caregivers to find their own solutions.

(a) Helplessness and Frustration

When a provider was unable to assist a caregiver, they experienced feelings of helplessness and frustration. This theme was particularly evident when the telephone call was anonymous and providers were unable to follow-up or call the caregiver back. The following quote clearly illustrates this sense of frustration.

... over the phone, there's only so much I can do to really help someone. I mean, I can't be there if someone is extremely agitated or repeating questions over and over. And I can hear it in their voice that they're just at the end of their rope – the caregiver. I feel somewhat limited in what I can really offer them. You know, I can talk to them and I can listen to them and maybe make them feel a little bit better for the moment, but then they hang up and they're still in that situation. I suppose also a limitation is that it is anonymous. And, in a way, I mean people can... I don't necessarily know who I'm talking to, and so it could just be a one-time thing. But I could get a pretty distressing phone call, not have a clue who I'm speaking to, and then I hang up and that's it. I'll never know what happened, unless they choose to call back (Provider #4).

The provider affiliated with the organization that offered non-anonymous telephone support noted that knowing the caregiver and his/her situation was definitely a

strength of their telephone support service, as it assisted her to better meet the needs of the caregivers.

The other strength that we talked about was that we do know the relatives. And so because we know the relatives personally, I think that they (the caregivers) would be able to say: "I'm going to call about this because they've (the telephone support providers) probably have run into this themselves"... And we also know the caregivers. So we know different personality traits and things that the caregiver might be private about ... as well as the things that the caregiver might be open about ... cause the client is the caregiver, and the client is also our adult in care (Provider #2).

The loss of context associated with a telephone interaction was also cited as a cause of helplessness. Providers described this loss of context as not being able to see how the caregiver was reacting to, or receiving their advice or input, and not being able to physically respond to the caregiver's reactions (especially when they were upset or angry).

One of the main limitations that I did run into ... is that you cannot see the person, so you cannot see the expressions on the client's face, their mood. You sometimes can't get a feeling, you know, about how things are being received (Provider #4).

(b) Empowering Caregivers

Providers relished being able to help others. They enjoyed the feeling of empowering caregivers to cope with difficult caregiving situations. The following excerpt demonstrates this theme.

Empower them to make their own referrals, to look for their own solutions. To choose from what's available in the community. For instance, a support group is not for everyone. There's a readiness for respite, to accept help in the home or outside of the home (Provider #4).

Discussion

The context of caregiving as revealed in this study included both negative and positive dimensions. Caregivers described negative dimensions such as “no life” and role isolation, being “locked in” and lonely, and deteriorating physical and mental health. Blended in with the negative experiences of caregiving, were positive reactions to providing care such as “feeling good” about their responsibilities as a caregiver. This is consistent with the literature that conceptualizes caregiving as a complex process, characterized by multiple dimensions and constructs (Kane & Kane, 2000).

This study revealed several key dimensions of the intervention of telephone support. The intervention is currently failing to meet the needs of caregivers who require this service beyond the eight-hour workday, and whose native tongue is other than English. However, the findings from this study demonstrate the ability of telephone support to meet some of the principal needs of caregivers. For example, the intervention can meet the need for information and advice, referral and assistance to navigate the health care system, emotional support, and the need for a caregiver intervention to be as convenient as possible. Some of the dimensions of telephone support have the ability to minimize negative effects of caregiving such as role isolation, loneliness, and deteriorating health, while fostering positive aspects such as “feeling good” about one self and one’s abilities (self-esteem and mastery).

Dimensions of Caregiving and Telephone Support

Role Isolation and Convenience of Support

Caregivers expressed “no life” and role isolation as negative determinants of caring for a person with dementia, which is consistent with the literature (Silverstein et al., 1993; Skaff & Pearlin, 1992). Caring for an individual with dementia is a 24-hour, seven day per week commitment, requiring supervision at all times. It is common for caregivers to become isolated in their role as the primary caregiver as they commit the majority of their time and energy to this role. As a result, there is less time to commit to other activities and people in their lives, thereby contributing to a loss of self (loss of identity), and increased levels of stress and depression.

Caregiver interventions such as education sessions and support groups are accessed during times that caregivers are relieved from their caregiving responsibilities (and there is someone else to supervise their loved one). Although caregivers appreciated and found other caregiver interventions very helpful (ie., respite care, support groups, educational sessions, day program), they alluded to the hassles and stresses associated with these services, and the convenience of the telephone support intervention. Current literature supports the need for caregiver support programs to be as convenient as possible, as care receiver resistance, reluctance of the caregiver to accept the intervention, hassles for the caregiver, and concerns over the quality of care have been cited as barriers to existing caregiver support programs (Wehtje Winslow, 2003). Telephone support is expense-free for caregivers, and can be accessed during “caregiving time” – so that when caregivers do receive some help or relief from their role as a

caregiver, they are free to participate in activities for themselves. This is crucial given the demanding and stressful nature of caring for someone with dementia. Interventions targeted for this population should aim to minimize the stresses associated with caregiving – not add to them.

Loneliness and Companionship

The findings of this study revealed that telephone support provides the companionship that caregivers crave. Loneliness is common among caregivers of persons with dementia as supervision is required all day and all night, every day and every night. They are only able to leave the house when someone else is available to assume the care of their loved one. The caregivers in this study reported being lonely even in the company of the care recipient, as they were unable to have a coherent conversation with their loved ones, and were seldom acknowledged for their knowledge or efforts. Telephone support was described as a service in which they were always connected to someone who would listen and respond to their concerns, which provided companionship in the comfort of their own home. Telephone support helps minimize the negative consequence of loneliness.

Deteriorating Health And Information, Navigation and Referral

As revealed in this study, many of the caregivers were experiencing declining physical health and a decrease in psychological well-being. Caregiver burden is a commonly recognized phenomenon defined as "the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for

impaired adults" (George & Gwyther, 1986, p. 253). Each caregiving situation is unique, and the perceived level of burden experienced by each dementia caregiver varies. Therefore, it is important to acknowledge that each situation requires a different combination of supports, based on the individualized needs of the caregiver. The findings of the study indicated that one of the main goals of telephone support is to empower caregivers. By empowering caregivers to navigate through the health care system, make their own referrals, and select their own combination of formal and informal supports, they are able to better cope with their individualized sources of burden, and enhance their levels of physical and psychological health. It has been demonstrated that telephone support increases the use of additional community services (Coyne et al., 1995).

This is consistent with current caregiving literature that affirms that existing and future caregiver support interventions should foster a caregiver's knowledge and abilities (or levels of mastery), and not just attempt to "alleviate or eliminate" negative effects such as burden, associated with the caregiving experience (Acton & Kang, 2001; Sorenson et al., 2002). Overall findings from nine systematic reviews on caregiver interventions revealed that most current caregiver support interventions are focused on only reducing the negative effects of caregiving, and unfortunately, have little or no effect on caregiver burden (Acton & Kang; Bourgeois et al., 1996; Cooke et al., 2001; Knight et al., 1993; Pusey & Richards, 2001; Roberts et al., 2000; Schulz et al., 2002; Sorenson et al., Yin et al., 2002.). Current literature now reveals that quality caregiving can coexist with caregiver burden (Greenberger & Litwin, 2003). This is crucial,

especially given the chronic nature of dementia - caregiving burden may never be readily reducible.

Feeling Good and Emotional Support

The findings of this study revealed that caregivers valued the on-going encouragement, reassurance, and acknowledgement of their caregiving efforts, provided through telephone support. When they were feeling uncertainty related to a caregiving incident, fed up, frustrated or upset, they appreciated the immediate response of a caring professional. This is consistent with the findings of a study completed by Mahoney, Tarlow, Jones, Tennstedt, & Kasten, (2001) that demonstrated a caregiver's preference for human interaction, as opposed to a voice response system offered over the telephone.

The intervention of telephone support does assist in decreasing some of the negative effects associated with caring for a person with dementia, but also fosters a sense of mastery within caregivers through the on-going encouragement and reassurance. By acknowledging the continuous efforts and hard work that the caregiver has provided, and commending them for their outstanding commitment to their loved one, telephone support providers can heighten a caregiver's level of self-esteem. This dimension of telephone support is congruent with literature that has recommended that future caregiver support interventions strive to both minimize the negative consequences of caregiving, and also focus on the enhancement of positive psychological factors associated with providing care to a family member or friend (Cohen et al., 2002; Kramer, 1997).

Study Limitations and Implications for Future Research

Although strategies were employed to strengthen the credibility of the research, this study was not without its limitations. First, a couple of potential sources of data related to the intervention of telephone support were not collected. For example, it was planned that statistical data on all the clients who had received telephone support from these agencies over the past year would be collected. It was hoped that data such as the number of calls per client, nature of calls and length of calls, as well as demographic data about the caregivers (ie., age, gender, occupation, living arrangement) would be collected. As a result of changes at the organizational level and the lack of documentation records, access to this data was not possible. However, demographic data from the caregivers who were interviewed were collected, via a simple data collection tool that was created specifically for this study (See Appendix J for demographic data collection tool). It was also anticipated that the methods would include audio-tapes and analysis of actual telephone support conversations for the purpose of obtaining a more in-depth understanding of the interaction between the provider and the caregiver. However, it was not possible to negotiate access to this data source for this study.

Second, the convenience sample of caregivers referred by the agencies included only Caucasian females residing in urban settings. Future qualitative research should explore the phenomenon of telephone support from the perspectives of both male and female caregivers, people of Caucasian and other ethnic backgrounds, and rural and urban caregivers, as all these factors have the potential to influence experiences of telephone support (Connell & Gibson, 1997; Navaie-Waliser, Spriggs, & Feldman,

2002). Data describing the income and education level of the caregivers should be collected in future research, as this is helpful for determining reasons for accessing telephone support and other services available in the community (Noonan & Tennstedt, 1997).

Finally, it may have been helpful to conduct interviews with the caregivers at a few points in time throughout their experience. This information would highlight the changing needs throughout the caregiving process, and enhance understanding of any trends or patterns throughout the process of dementia caregiving.

Practice Implications

It was evident in this study that caregivers appreciated and were grateful for the intervention of telephone support. They specifically cherished the sense of companionship offered through this intervention, and knowing that they were always connected to someone who cared and could help. Although it was revealed that current caregiver interventions such as educational sessions, support groups, and respite are all helpful, telephone support was described as an intervention that has the ability to meet the various needs of caregivers, in the comfort of their own home. Through the telephone, providers are able to offer information and advice, specifically tailored to each unique caregiving situation, assist with referral and navigation through the system, and provide emotional support. Through this provision of information, referral, and emotional support, providers strive to empower each caregiver to successfully manage their unique caregiving experiences.

However, both the caregivers and providers identified a number of areas in which the intervention could be improved, and suggested a few implications for future telephone support provision. First, strategies to increase the availability of telephone support were recommended by most of the caregivers and providers included in this study. Consideration should be given to increasing the hours of service beyond week day hours of 9 am to 5 pm. The caregivers expressed that they would definitely use this service if it was available in the evening hours, and providers reinforced this by describing some of the messages left by the caregivers after hours. The need for a 24-hour service was indicated by half of the participants in this study. Similar to the study by Silverstein et al. (1993), only some of the caregivers suggested that telephone support be offered 24-hours each day.

Second, recruitment of providers who are proficient in languages other than English is another factor that should be considered in organizations that are currently offering or are planning to offer, telephone support programs. This would address one of the current limitations of telephone support, language barriers, which specifically affects those caregivers whose native tongue is other than English. This is consistent with findings from another study that revealed the need to expand telephone support services to include culturally and ethnically diverse populations (Silverstein et al., 1993).

Third, adequate training and support for providers of the service should include receiving education on safety issues (ie., how to deal with verbal harassment), and the provision of bereavement/grief counseling. Both situations were identified as

uncomfortable for the telephone support providers, and having some training and information beforehand might help to address some of this uneasiness.

The providers identified the importance of debriefing with colleagues after each of the support sessions, to validate their assessments and plans of care for the caregiver, and discuss any unanswered questions that remained after the call. Fourth, agencies should consider options such as this to support the providers who often feel helpless and frustrated. The providers also revealed the importance of the physical layout of the offices, for example, private rooms to minimize distraction and to promote confidentiality.

Fifth, careful consideration should be given to the advantages and disadvantages of an anonymous telephone support intervention. Knowing about the caregiver/care recipient situation prior to providing telephone support was viewed as helpful by both caregivers and providers, and having the ability to follow-up with caregivers was important to all of the providers, especially after difficult support sessions. This is not possible with an anonymous, caregiver-initiated service, which may be an option preferred by some caregivers. It was interesting to note that in this study, all three providers from the organization that provided the anonymous telephone support knew who most of the caregivers were, and the caregivers knew the providers. Finally, the need for regular evaluation of provider performance and caregiver satisfaction with services was identified as being a necessity in order to ensure that the intervention of telephone support continues to meet the needs of caregivers of persons with dementia.

The intervention of telephone support is a convenient method of meeting the needs of informal caregivers of persons with dementia. This service assists in reducing feelings of loneliness, and provides caregivers with the information and emotional support required to cope with the stresses associated with the caregiving process. This qualitative study embodies a very personal and subjective experience of the intervention of telephone support from the perspectives of those involved, and was most beneficial for achieving an enhanced understanding of this support service. It is an intervention that conveniently meets the dementia caregiver's needs for information, referral and emotional support. Most importantly, telephone support can be advantageous at any stage in the caregiving cycle, from initial selection of community supports, throughout the process of long term care placement, to the final stages of grief and bereavement.

References

- Acton, G., & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. *Research in Nursing and Health*, 24, 349-360.
- Bourgeois, M., Schulz, R., & Burgio, L. (1996). Interventions for caregivers of patients with Alzheimer's Disease: A review and analysis of content, process and outcomes. *International Journal of Aging and Human Development*, 43, 35-92.
- Brown, R., Pain, K., Berwald, C., Hirschi, P., Delehanty, R., & Miller, H. (1999). Distance education and caregiver support groups: Comparison of traditional and telephone groups. *Journal of Head Trauma Rehabilitation*, 14(3), 257-268.
- Cohen, C., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry*, 17, 184 - 188.
- Colantonio, A., Cohen, C., & Corlett, S. (1998). Support needs of elderly caregivers of persons with dementia. *Canadian Journal of Aging*, 17(3), 330 -345.
- Colantonio, A., Kositsky, A., Cohen, C., & Vernich, L. (2001). What support do caregivers of elderly want? Results from the Canadian study of health and aging. *Canadian Journal of Public Health*, 92(5), 376-379.
- Connell, C., & Gibson, G. (1997). Racial, ethnic, and cultural differences in dementia caregiving: Review and analysis. *The Gerontologist*, 37, 355-364.
- Cooke, D., McNally, L., Mulligan, K., Harrison, M., & Newman, S. (2001). Psychosocial interventions for caregivers of people with dementia: A systematic review. *Aging and Mental Health*, 5, 120-135.
- Coyne, A. (1991). Information and referral service usage among caregivers for dementia patients. *The Gerontologist*, 31, 384-388.
- Coyne, A., Potenza, M., & Broken-Nose, M. (1995). Caregiving and dementia: The impact of telephone helpline services. *American Journal of Alzheimer's Disease*, 10(4), 27-32.
- Creswell, J. (1998). *Choosing among five traditions: Qualitative inquiry and research design*. Newbury Park, CA: Sage.

- Davis, L. (1998). Telephone-based interventions with family caregivers: A feasibility study. *Journal of Family Nursing*, 4, 255-270.
- Durand, P., Krueger, P., Chambers, L., & Grek, A. (1995). Predictors of caregivers' dissatisfaction with community long-term care services for seniors: Results from the Canadian study of health and aging. *Canadian Journal of Public Health*, 86(5), 325-332.
- George, L., & Gwyther, L. (1986). Caregiver well-being: A multidimensional Examination of family caregivers of demented adults. *The Gerontologist*, 26, 253-259.
- Gitlin, L., Burzio, L., Mahoney, D., Burns, R., Zhang, S., Schulz, R., Belle, S., Czaja, S., Gallagher-Thompson, D., Hauck, W., & Ory, M. (2003). Effect of multicomponent interventions on caregiver burden and depression: The REACH multisite initiative at 6-month follow-up. *Psychology and Aging*, 18(3), 361-374.
- Goodman, C., & Pynoos, J. (1990). A model telephone information and support program for caregivers of Alzheimer's patients. *The Gerontological Society of America*, 30, 399-404.
- Grant, J., Elliot, T., Weaver, M., Bartolucci, A., & Newman Giger, J. (2002). Telephone interventions with family caregivers of stroke survivors after rehabilitation. *Stroke*, 33, 2060-2065.
- Greenberger, H., & Litwin, H. (2003). Can burdened caregivers be effective facilitators of elder care-recipient health-care? *Journal of Advanced Nursing*, 4, 332-341.
- Grunfeld, E., Glossop, R., McDowell, I., & Danbrook, C. (1997). Caring for elderly people at home: The consequences to caregivers. *Canadian Medical Association Journal*, 157, 1101-1105.
- Hartke, R., & King, R. (2003). Telephone group intervention for older stroke caregivers. *Topics in Stroke Rehabilitation*, 9, 65-81.
- Kane, R., & Kane, R. (2000). *Assessing older persons: Measures, meaning, and practical implications*. USA: Oxford University Press.
- Knight, B., Lutzky, S., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *Gerontologist*, 33, 240-248.

- Kramer, B. (1997). Gain in the caregiving experience: Where are we? What next? *The Gerontologist*, 37, 218-232.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.
- Mahoney, D., Tarlow, B., & Jones, R. (2003). Effects of an automated telephone support system on caregiver burden and anxiety: findings from the REACH for TLC Intervention Study. *The Gerontologist*, 43(4), 556-567.
- Mahoney, D., Tarlow, B., Jones, R., Tennstedt, S., & Kasten, L. (2001). Factors affecting the use of a telephone-based intervention for caregivers of people with Alzheimer's disease. *Journal of Telemedicine and Telecare*, 7(3), 139-148.
- Merlis, M. (2000). Caring for the frail elderly: An international review. *Health Affairs*, 19, 141-149.
- Miles, M., & Huberman, A. (1994). *Qualitative data analysis: A source book of new methods (2nd Ed.)*. Thousand Oaks, CA: Sage.
- Navaie-Waliser, M., Spriggs, A., & Feldman, P. (2002). Informal caregiving: Differential experiences by gender. *Medical Care*, 40(12), 1249-1259.
- Noonan, A., & Tennstedt, S. (1997). Meaning in caregiving and its contribution to caregiver well-being. *The Gerontologist*, 37, 785-794.
- Ory, M., Hoffman, R., Yee, J., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist*, 39, 177-185.
- Ploeg, J., Biehler, L., Willison, K., Hutchison, B., & Blythe, J. (2001). Perceived support needs of family caregivers and implications for a telephone support services. *Canadian Journal of Nursing Research*, 33(2), 43-61.
- Pusey, H., & Richards, D. (2001). A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging and Mental Health*, 5, 107-119.
- Roberts, J., Browne, G., Gafni, A., Varieur, M., Loney, P., & deRuijter, M. (2000). Specialized continuing care models for persons with dementia: A systematic review of the research literature. *Canadian Journal on Aging*, 19, 106-126.

- Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L., Belle, S., Burgio, L., Gitlin, L., Coon, D., Burns, R., Gallagher-Thompson, D., & Stevens, A. (2002). Dementia caregiver intervention research: In search of clinical significance. *The Gerontologist*, 42(5), 589-602.
- Short, L., & Saindon, E. (1998). Telehomecare: Rewards and risks. *Caring*, 17, 36-42.
- Silverstein, N., Kennedy, K., & McCormick, D. (1993). Telephone helpline for Alzheimer's disease: Information, referral and support. *American Journal of Alzheimer's Care and Related Disorders and Research*, 8(5), 28-36.
- Skaiff, M., & Pearlin, L. (1992). Caregiving: Role engulfment and loss of self. *The Gerontologist*, 32, 656-664.
- Skipwith, D. (1994). Telephone counselling interventions with caregivers of elders. *Journal of Psychosocial Nursing*, 32, 7-12.
- Sorenson, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42(3), 356-372.
- Stake, R. (1995). *The art of case study research*. Thousand Oaks: Sage Publications.
- Stewart, M., Hart, G., Mann, K., Jackson, S., Langille, L., & Reidy, M. (2001). Telephone support group interventions for persons with hemophilia and HIV/AIDS and family caregivers. *International Journal of Nursing Studies*, 38, 209-225.
- Strawn, B., & Hester, S. (1998). Telecare: A social support intervention for family caregivers of dementia victims. *Clinical Gerontologist*, 18, 66-69.
- Wehtje Winslow, B. (2003). Family caregivers' experiences with community services: A qualitative analysis. *Public Health Nursing*, 20, 341-348.
- Yin, T., Zhou, Q., & Bashford, C. (2002). Burden on family members - Caring for frail elderly: A meta-analysis of intervention. *Nursing Research*, 51(3), 199-208.

CHAPTER FIVE

Thesis Conclusion

This sandwich thesis describes the entire research process of a qualitative case study seeking to understand the intervention of telephone support for dementia caregivers. The thesis consisted of five chapters: an introductory chapter; a chapter outlining the literature reviewed for this study; a chapter describing the methods and challenges associated with conducting qualitative caregiver research; a chapter revealing the findings of the study; and this concluding chapter. The three middle chapters that make up the “meat” of this sandwich thesis have been written as articles or separate entities, and will be submitted for publication in the near future. Each of the three articles has been written in expanded form for the purpose of including all details that would otherwise appear in a standard PhD dissertation.

The purpose of this concluding chapter is to briefly summarize the contents of each chapter, highlight the overall conclusions from the study, and describe the importance of conducting caregiver research that acknowledges both the positive and negative outcomes experienced while providing care to a loved one. The chapter will conclude with implications for future practice and research.

Contents of Each Chapter

Literature on caregiver interventions, telephone support, and telephone support as an intervention for caregivers of persons with dementia was reviewed and appraised for

quality in Chapter Two. The research to-date indicated that current interventions (respite, support groups, counselling and educational sessions) have little or no effect on negative outcomes such as caregiver burden, and a larger impact on positive outcomes such as a caregiver's knowledge and ability (or levels of mastery). It has also been suggested that those who care for persons with dementia require a different intervention strategy than their counterparts, as they experience an assortment of unique and challenging demands (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). The research reviewed for the purpose of this study indicated that telephone support has the potential to positively influence one's overall knowledge and ability (or mastery), however it is difficult to confirm this from the limited amount of quantitative research on telephone support for dementia caregivers, and the lack of qualitative research in this area.

The lack of credible, qualitative research exploring telephone support in the caregiving literature was the primary driving force for this study. The methods of a qualitative case study seeking to better understand the intervention of telephone support are described in Chapter Three. The study revolves around three central questions, which aim to identify the multiple dimensions of the intervention, and illuminate some of the experiences of both receivers and providers of telephone support. The aim of this new knowledge is to better understand how this intervention impacts the total dementia caregiving experience. The third chapter concludes with some of the challenges associated with conducting qualitative research with the caregiver population.

The findings from the study are summarized in Chapter Four. The main dimensions of telephone support revealed from this study included meeting the needs for

information, referral to other community services, emotional support, and the need for dementia caregiver support interventions to be as convenient as possible. Caregivers' experiences with telephone support revealed the importance of the companionship offered through this intervention. Providers identified experiences that detailed their ability to empower caregivers through telephone support, to seek their own information and make their own referrals and links to other community services. It was also revealed from both caregivers and providers interviewed in this study, that the intervention of telephone support is valuable at various stages of the dementia caregiving experience, which is crucial given its ever-changing nature.

Overall Conclusions

In View of Existing Caregiving Literature

Current caregiving literature is largely grounded in sociological perspectives of stress, which results in the majority of outcome measurements and caregiver interventions emphasizing the negative aspects of caregiving, such as caregiver burden and depression (Kane & Kane, 2000). However, recent research has revealed that existing caregiver support interventions have little or no effect on caregiver burden, and a larger impact on a caregiver's knowledge and ability (or levels of mastery). Therefore, if a caregiver intervention is to be successful, it must continue to acknowledge and foster a caregiver's abilities, and not just attempt to "alleviate or eliminate" the negative effects associated with the caregiving experience (Acton & Kang, 2001; Sorenson, Pinquart, & Duberstein, 2002; Schulz et al., 2002; Yin, Zhou, & Bashford, 2002). This is especially

important in the case of dementia caregivers, as burden may never be readily reducible, given the chronic and progressive nature of the illness.

The findings from this study confirmed three things. First, telephone support meets the information and emotional needs of dementia caregivers, which enhances their ability and level of mastery to provide care. As revealed from the interview data, this sense of mastery translates into an increased level of confidence and self esteem in their role as a dementia caregiver. Second, telephone support provides a connection to other interventions and sources of support within the community, which can help alleviate some of the negative effects associated with caregiving. According to the caregivers and providers in this study, this intervention assisted in reducing feelings of loneliness, and provided caregivers with the support required to cope with the stresses and burdens associated with the caregiving experience.

Finally, telephone support can be advantageous at any stage in the caregiving process. Current literature describes caregiving as an ongoing process, with caregiver needs changing throughout the experience (Gaugler, Davey, Pearlin, & Zarit, 2000). Telephone support has the ability to meet the ongoing needs of dementia caregivers, throughout the stressful experience of caregiving. It is an intervention that is unconditional, and can be accessed in the beginning stages of dementia, during moderate to severe impairment, can assist the caregiver after the care recipient has been placed in a long-term care facility, and can still offer support after the person with dementia has deceased. The ongoing convenience and companionship associated with this intervention warrants continued use of this service throughout the entire caregiving experience.

Importance of Caregiving Research

According to a Canadian study, 87% of caregivers are informal and comprised mostly of immediate family members (Canadian Study of Health and Aging, 1994).

Because of the aging of the world's population, it is expected that the number of informal, community-based caregivers will increase dramatically. It is also expected that the number of people suffering with dementia will increase. In 1991-1992, the prevalence of all types of dementia among Canadians was 252 600 persons, which is expected to double to about half a million by 2013 (Canadian Study of Health and Aging Working Group, 1994; Hill, Forbes, Berthelot, Lindsay, & McDowell, 1996).

Due to recent changes in the health care and social services systems (ie., shorter hospital stays, waiting lists for long term care placement, home care service cutbacks, and a greater use of outpatient treatments), further pressure has been added to the caregiving capabilities of families (Cranswick, 1997). Pressure is experienced especially by caregivers of persons with dementia, as persons with chronic mental illnesses require either supervision and assistance 24-hours per day in order to remain in the community, or placement in a hospital or long term care setting (if available). This population continues to experience the negative repercussion of current health care restructuring.

For this reason alone, future research with dementia caregivers is essential, especially if health care professionals and investigators are to develop, evaluate, and improve existing caregiver interventions. Every caregiving experience is different, and reasons for accessing both formal and informal supports vary based on how family caregivers perceive their experiences. Recent literature has shown that measuring only

burden and developing interventions targeted at burden, does not necessarily lead to the management of burden (Acton & Kang, 2001; Sorenson et al., 2002). Lack of attention to the positive aspects of the caregiving experience limits the ability of health care professionals to design beneficial and efficacious programs for caregivers. In order to evaluate and improve existing caregiver support interventions, and successfully meet the needs of dementia caregivers, the following recommendations for future research and practice are suggested.

Recommendations for Research

This study was the first qualitative approach to explore in-depth, the subjective experiences of both dementia caregivers and providers of telephone support, and is also unique because it strives to understand *how* caregiver outcomes result from this intervention, as opposed to simply identifying what the outcomes are as the result of telephone support. In more ways than one, this case study makes a considerable contribution to the existing literature on telephone support and interventions for dementia caregivers.

From the literature review, it was evident that additional research is required to understand the effectiveness and perceived impact of caregiver telephone support, specifically for caregivers of persons with dementia. This study provides a source of credible qualitative research, which is the best method to heighten understanding of the perceived impact of telephone support. From this new knowledge, quantitative studies of large scale and high quality design (ie., randomized controlled trials) can be undertaken

to produce more definitive conclusions about the effectiveness of telephone support for caregivers of persons with dementia. Currently, the high quality randomized controlled trials focus on either an interactive voice response system (Mahoney, Tarlow, & Jones, 2003), or on populations other than dementia caregivers (Grant, Elliot, Weaver, Bartolucci, & Newman Giger, 2002), or refer to telephone support as only a control intervention (Gitlin et al., 2003). Clearly, there is a great need for large scale, strong quantitative designs to determine the effectiveness of the telephone support intervention for caregivers of persons with dementia. As well, it would be beneficial to complete an economic analysis to determine if the intervention of telephone support helps to reduce health and social service related costs, and whether or not it is feasible to offer telephone support as a 24-hour service.

Research that is either quantitative or qualitative, and longitudinal would be helpful in determining the effect of telephone support over time, and the changing caregiver experiences with telephone support, especially as the dementia illness progresses and the demands of providing care increase and become more difficult. Mixed studies of both quantitative and qualitative research combined would be valuable as they would provide evidence of the effectiveness, efficiency, and feasibility of the telephone support intervention, while collecting personal insight and detail from those participants involved in receiving and providing the intervention.

Research with caregivers is crucial, albeit challenging and distressing at times, especially if healthcare professionals are to succeed in designing and evaluating existing caregiver interventions, and in this case, build knowledge in the area of dementia care.

As one-to-one telephone support from a professional was reported as being successful in meeting the needs of dementia caregivers in this study, future research should continue to explore its effectiveness with other caregiver populations. In addition, research should continue to explore and examine telephone support programs that offer either peer or professional, or a combination of the two types of assistance, to determine which is most helpful to caregivers.

Finally, implications for future caregiving research should include the acknowledgement of both positive outcomes of the caregiving experience (such as self-esteem, personal meaning, and mastery), in addition to negative outcomes such as depression and burden. In order to identify strengths and weaknesses of existing caregiver interventions such as telephone support, the research must include an improved conceptualization of all variables and outcomes (Czaja, Schulz, Lee, & Belle, 2002). One method of accomplishing this would be to use a framework that outlines the process of caregiving, for example, using the conceptual model proposed by Noonan and Tennstedt (1997), as it acknowledges the concept of meaning in caregiving. Given the current state of caregiving research, this model has the potential to assist health care professionals to better understand the process of caregiving, and consequently evaluate the effectiveness and impact of existing caregiver interventions.

Recommendations for Practice

A number of practice implications for future telephone support provision were identified by the caregiver and telephone support provider participants in this study.

First, providers emphasized the importance of education on safety issues (for example, how to deal with verbal harassment), and bereavement/grief counseling, when training new providers of telephone support. As well, it was suggested that recruitment of providers who are proficient in other languages should be considered in organizations that are currently offering or are planning to offer, telephone support programs. This would eliminate one of the current limitations of telephone support, language barriers, which specifically affects those caregivers whose native tongue is other than English. Second, the providers identified the importance of the physical layout of the offices, for example, private rooms were suggested to minimize distraction and to promote confidentiality.

Third, the caregivers and providers cited hours of availability as a limitation of telephone support. Caregivers expressed that they would definitely use this service if it was available in the evening hours, and providers reinforced this by describing the type and number of messages left by the caregivers after hours. Knowing about the caregiver/care recipient situation prior to providing telephone support was helpful, and having the ability to follow-up with caregivers was important to all of the providers. What was really important to the caregiver was the sense of companionship – someone to share their caregiving experiences with. What was also interesting in this study was that three of the four providers had previous caregiving experience, caring for either a parent or a spouse. So in essence, they had the ability to support the caregivers as both a professional, and as a peer.

Fourth, the need for regular evaluation of provider performance and appraisal of services was identified as being a necessity in order to ensure that the intervention of telephone support continues to meet the needs of caregivers of persons with dementia. At the time of this study, neither agency was collecting statistical data related to the number of calls, length of calls, time of calls etc., nor were they involved in regular evaluation of the service. This information and evaluation is crucial in increasing knowledge of the intervention, and determining whether or not it is meeting the needs of the dementia caregivers.

Currently, this intervention is meeting some of the needs of dementia caregivers, for example, the need for information, referral, emotional support, and the need for caregiver assistance to be as convenient as possible. The participants involved in this study had access to a toll-free telephone support phone number, which added to the convenience of this support intervention. The use of this resource assumes that most caregivers have access to a telephone. It is also important to note that the above implications for future practice should be viewed as tentative, given the limited sample size and restricted data sources.

Finally, the caregivers and providers interviewed in this study also stressed the importance of the caregiver support program as a whole, including services such as Day Programs, support groups, educational sessions and respite, in addition to telephone support. This is consistent with the findings from Gitlin et al., (2003), that reported “there is no single, easily implemented, and consistently effective method for eliminating the multiple stresses of providing care to persons with dementia” (p. 372). Although

telephone support was described as the “in-betweener” intervention, and the caregivers strongly valued the convenience, companionship, and the intervention’s ability to meet their needs, they appreciated the variety of services and multiple options of assistance

Current Health Care Challenges

One of the challenges in health care today is the increased demand for home care services as a result of an aging population, and hospital downsizing and restructuring. Individuals with dementia and their caregivers can benefit substantially from community and home care services, particularly if they want to prevent or delay institutionalization or long-term care placement. For those individuals who are on waiting lists for long-term care placement, the need for long-term care beds currently exceeds availability, and home care services are required to ensure both the personal care and safety of the individual while they remain at home (Carefoote, 1998).

In addition to the increased need for home care services, is the issue of decreased human resources (ie., community nurses and personal support workers), as the result of wage disparity between the hospital and community sectors. Human resources shortages are a serious concern for CCACs (PriceWaterhouseCoopers, 2000). The shift of public dollars from the institutional to the community care sector has not kept pace with the increased demand for community services, leading to cost containment strategies, such as home care service cutbacks and strict criteria for home care service eligibility (Carefoote, 1998).

Barriers to access for particular client groups continue to exist in all regions of the province, and waiting lists remain for therapies, nurses, and homemaking services (PriceWaterHouseCoopers, 2000). Driven by funding, cost containment strategies such as the rationing and reduction of home care service are producing more harm than good to the overall health care needs of the community. Recent research has demonstrated that eliminating maintenance and preventative home care services is not cost-effective, and may lead to increased costs in the overall health care system, as well as create suffering and emotional distress for a significant portion of the people who are cut from care and their informal caregivers (Fassbender, 2001; Hollander & Tessaro, 2001). Most of the caregivers interviewed in this study described concerns relating to the limitations of the home care system. In order to support the growing number of dementia caregivers at a time when public and private agencies cannot offer adequate home care assistance or respite, chronic hospital or immediate placement beds, it is crucial to evaluate and improve existing caregiver support programs and develop new strategies to assist this population.

Concluding Remarks

The intervention of telephone support is a convenient method of meeting the needs of informal caregivers of persons with dementia. This service assists in reducing feelings of loneliness, and provides caregivers with the information and emotional support required to cope with the stresses associated with the caregiving process. Telephone support can be advantageous at any stage in the caregiving cycle, from initial

selection of community supports, throughout the process of long term care placement, to the final stages of grief and bereavement. This qualitative study embodies a very personal and subjective experience of the intervention of telephone support from the perspectives of those involved, and was most beneficial for achieving an enhanced understanding of this support service. It is an intervention that not only fosters a caregiver's level of mastery, but also assists in the management of negative outcomes such as burden. Most importantly, it provides a valuable connection - a telephone connection ... to someone who cares for those who provide care.

REFERENCES

- Acton, G., & Kang, J. (2001). Interventions to reduce the burden of caregiving for adult with dementia: A meta-analysis. *Research in Nursing and Health*, 24, 349-360.
- Canadian Study of Health and Aging. (1994). Patterns of caring for people with dementia in Canada. *Canadian Journal on Aging*, 14, 470-487.
- Canadian Study of Health and Aging Working Group. (1994). Study methods and prevalence of dementia. *Canadian Medical Association Journal*, 150(6), 899-912.
- Carefoote, R. (1998). Health care issues: Managing services and people in home care: Today's challenge. *Canadian Journal of Nursing Administration*, 11(3), 77-94.
- Colantonio, A., Cohen, C., & Corlett, S. (1998). Support needs of elderly caregivers of persons with dementia. *Canadian Journal of Aging*, 17(3), 330-45.
- Colantonio, A., Kositsky, A., Cohen, C., & Vernich, L. (2001). What support do caregivers of elderly want? Results from the Canadian Study of Health and aging. *Canadian Journal of Public Health*, 92(5), 376-379.
- Crabtree, B., & Miller, W. (1992). *Doing qualitative research*. Newbury Park, CA: Sage.
- Cranswick, K. (1997). Canada's caregivers. *Canadian Social Trends*, 47, 2-6.
- Czaja, S., Schulz, R., Lee, C., & Belle, S. (2002). A methodology for describing and decomposing complex psychosocial and behavioural interventions. *Psychology and Aging*, 18(3), 385-395.
- Fassbender, K. (2001). *Cost implications of informal supports (Substudy 3)*. British Columbia, Canada: National Evaluation of the Cost-Effectiveness of Homecare.
- Gallicchio, L., Siddiqi, N., Langenberg, P., & Baumgarten, M. (2002). Gender differences in burden and depression among informal caregivers of demented elders in the community. *International Journal of Geriatric Psychiatry*, 17, 154-163.
- Gaugler, J., Davey, A., Pearlin, L., & Zarit, S. (2000). Modeling caregiver adaptation over time: The longitudinal impact of behaviour problems. *Psychology and Aging*, 15(3), 437-450.

- George, L., & Gwyther, L. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist*, 26, 253-259.
- Gitlin, L., Burgio, L., Mahoney, D., Burns, R., Zhang, S., Schulz, R., Belle, S., Czaja, S., Gallagher-Thompson, D., Hauck, W., & Ory, M. (2003). Effect of multi-component interventions on caregiver burden and depression: The REACH multi-site initiative at 6-month follow-up. *Psychology and Aging*, 18(3), 361-374.
- Goodman, C., & Pynoos, J. (1990). A model telephone information and support program for caregivers of Alzheimer's patients. *The Gerontologist*, 30, 399-404.
- Grant, J., Elliot, T., Weaver, M., Bartolucci, A., & Newman Giger, J. (2002). Telephone interventions with family caregivers of stroke survivors after rehabilitation. *Stroke*, 33, 2060-2065.
- Greenberger, H., & Litwin, H. (2003). Can burdened caregivers be effective facilitators of elder care-recipient health-care? *Journal of Advanced Nursing*, 41, 332-341.
- Grunfeld, E., Glossop, R., McDowell, I., & Danbrook, C. (1997). Caring for elderly people at home: The consequences to caregivers. *Canadian Medical Association Journal*, 157, 1101-1105.
- Hill, G., Forbes, W., Berthelot, J., Lindsay, J., & McDowell, I. (1996). Dementia among seniors. *Health Reports*, 8(2), 7-10.
- Hollander, M., & Tessaro, A. (2001). *Evaluation of the maintenance and preventative model of home care* (Final Report). British Columbia, Canada: Hollander Analytical Services.
- Kane, R., & Kane, R. (2000). *Assessing older persons: Measures, meaning, and practical implications*. USA: Oxford University Press.
- Keen J., & Packwood, T. (1996). Case study evaluations. In N. Mays & C. Pope (Eds.), *Qualitative research in healthcare*. London: B.M.J. Publishing Group.
- Kramer, B. (1997). Gain in the caregiving experience: Where are we? What next? *The Gerontologist*, 37, 218-232.
- Mahoney, D., Tarlow, B., & Jones, R. (2003). Effects of an automated telephone support system on caregiver burden and anxiety: Findings from the REACH for TLC Intervention Study. *The Gerontologist* 43(4), 556-567.

- Merlis, M. (2000). Caring for the frail elderly: An international review. *Health Affairs*, 19, 141-149.
- Noonan, A., & Tennstedt, S. (1997). Meaning in caregiving and its contribution to caregiver well-being. *The Gerontologist*, 37, 785-794.
- Ory, M., Hoffman, R., Yee, J., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist*, 39, 177-185.
- Ploeg, J., Biehler, L., Willison, K., Hutchison, B., & Blythe, J. (2001). Perceived support needs of family caregivers and implications for a telephone support services. *Canadian Journal of Nursing Research*, 33(2), 43-61.
- PriceWaterhouseCoopers (2000). *A review of community care access centres in Ontario: Final Report*. Ottawa: Ontario Ministry of Health and Long Term Care.
- Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L., Belle, S., Burgio, L., Gitlin, L., Coon, D., Burns, R., Gallagher-Thompson, D., & Stevens, A. (2002). Dementia caregiver intervention research: In search of clinical significance. *The Gerontologist*, 42(5), 589-602.
- Short, L., & Saindon, E. (1998). Telehomecare: Rewards and risks. *Caring*, 17, 36-42.
- Sorenson, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42(3), 356-372.
- Stewart, M., Hart, G., Mann, K., Jackson, S., Langille, L., & Reidy, M. (2001). Telephone support group interventions for persons with hemophilia and HIV/AIDS and family caregivers. *International Journal of Nursing Studies*, 38, 209-225.
- Yin, T., Zhou, Q., & Bashford, C. (2002). Burden on family members - Caring for frail elderly: A meta-analysis of intervention. *Nursing Research*, 51(3), 199-208.

APPENDICES

Appendix A: Summary of Studies Reviewed

A 1: Evaluation Studies

Author (s), (Year) & Country	Study Design & Sample Characteristics	Intervention	Conceptual Framework & Outcome Measures	Findings
Brown et al. (1999). Canada	-quasi-experimental design -131 caregivers of an adult person with a brain injury placed in either a telephone group or in an "onsite group" -91 caregivers completed all questionnaires (69%) -88% caregivers were female -mean age of 48 years -50% of caregivers were spouses	Type: Telephone groups and on-site groups to provide education, skill development, & counselling. Education videos sent to groups in year 2. Duration: 20 groups conducted over a 2 year period, one evening session for 9-10 weeks (each lasting 1.5-2 hrs) -first meeting for telephone group was face to face Provider: both groups were led by a psychologist, neuropsychologist, or a social worker from within the brain injury program	-no framework cited -Family Assessment Device (FAD); Caregiver Burden Inventory (CBI); Profile of Mood States (POMS); -administered 2 months prior to groups; at first group session; at last group session; and 6 months after last group session	-no significant improvement on FAD or CBI -significant improvement in POMS for both groups -similar improvements for on-site and telephone groups -telephone groups rated higher satisfaction than on-site group
Coyne, Potenza & Broken Nose (1995). U.S.A	-RCT - 98 caregivers for dementia patients who called a toll free New Jersey state-wide help line - 52% returned Time 1 and 2 questionnaires - 88% caregivers were female - mean age was 50 years	Type: telephone help-line (information, referral, education, counselling) Duration: Intervention group: staff made 2x/week x 8 weeks -Control group: spoke with staff once Provider: staff had extensive experience with dementia patients & caregivers in a university or community mental health centre setting	- no framework cited -Zarit Burden Interview -Zung Depression scale -number of community services used -mailed follow-up at 8 weeks	-Extended telephone contact group: increased use of community services in comparison to control subjects -no difference in depression -decrease in levels of burden

Author (s), (Year) & Country	Study Design & Sample Characteristics	Intervention	Conceptual Framework & Outcome Measures	Findings
Davis (1998). U.S.A.	-Pilot study (before/after) with content analysis and t-test -20 dementia caregivers recruited from memory disorder clinic -85%completed follow-up assessments -mean age of caregivers: 57.2 years -75% were women -60% were Caucasian	Type: home visit made prior to telephone interventions; this was intensive 2 hour training sessions focused on problem- solving and use of tip sheets -phone calls to caregivers to review problems & reinforce each caregiver's problem solving ability Duration: nurses contacted each caregiver by phone 1/ wk (x 12)(45-60 mins.) Provider: community health nurses with graduate degrees (no experience in dementia care	-no framework cited -Revised Memory and Behaviour Problem Checklist -Rational Problem- Solving Inventory -use of social support (interpersonal support evaluation list) -Geriatric Depression Rating scale -Caregiver Life Satisfaction -administered at baseline and 12 weeks	-no changes in caregiver's problem solving styles, number of problem behaviours, or reactions of caregivers to those behaviours -caregivers used more social support, had decreased depression symptoms, & an increase in life satisfaction
Gitlin et al. (2003). U.S.A.	-multi-site RCT - 6 sites; 1222 caregivers of persons with Alzheimer's and related dementias -sample comprised of Caucasian, Blacks & Hispanics	Type: compared skill training, telephone- linked computer, behaviour care, family structural multisystem in-home intervention, caregiving/coping classes & environmental skills with minimal support conditions (telephone support & written info. on dementia). Duration: 6-12 mos. Provider: geriatric nurse specialists, interventionalists, therapists	-Pearlin's framework (1990) & Stress & Coping (Lazarus & Folkman, 1984) -Revised Memory & Problem Behaviour Checklist -depression CES-D -follow-up at 6 months	-no statistically significant effects for any 1 intervention for burden or depression -pooled treatment effect was significant for burden (but the difference was small); & not statistically significant for depression -interventions should be multi- component and tailored

Author (s), (Year) & Country	Study Design & Sample Characteristics	Intervention	Conceptual Framework & Outcome Measures	Findings
Goodman & Pynoos (1990). U.S.A.	-RCT/comparison b/w telephone support group vs. mini-info phone sessions -caregivers of persons with Alzheimer's -all caregivers recruited through agency contacts and media announcements -average age was 64.5 years; most were married and Caucasian, female and spouse of Alzheimer's patient. -31 caregivers in peer telephone network -35 caregivers in lecture component	Type: peer telephone networks & telephone accessed informational lectures (Alzheimer's disease) -support group over the telephone (informational and emotional support needs of caregivers) Duration: -caregivers in peer telephone network of 4 or 5 caregivers who called each other (approx. 15 mins.) in a rotating pattern over 12 wks -other caregivers assigned to lecture component and listened to 12 telephone accessed taped lectures about Alzheimer's over 12 wks Provider: peers	-No framework cited -Memory & Behaviour Problem Checklist -Burden Interview (Zarit) -Caregiver Elder Relationship Scale -Mental Health -Social Support -knowledge of Alzheimer's disease -baseline & 3 month follow- up	Results indicated info. gain, increased perceived social supports, and increased satisfaction with social supports in both groups -no benefit found re: relief from caregiver burden, caregiver elder relationships or mental health -peer supports were substituted for family and friend support
Grant et al. (2002). U.S.A.	-randomized, 3 group. repeated- measure control trial -74 primary caregivers of stroke survivors -mean age: 56 years -91% female -74% Caucasian	Type: social problem-solving therapy via telephone Duration: -initial 3 hr home visit between an RN & caregiver, then weekly telephone contact (weekly x 1 month; bi-weekly 2nd & 3rd month) Provider: graduate research assistant	-No framework cited -general Health (SF-36) -social problem solving abilities -satisfaction with health care -depression (CES-D) -preparedness for caregiving scale -caregiving burden scale	-compared sham and control groups; caregivers who received social problem-solving therapy (phone) had better problem-solving skills and preparedness, less depression, role isolation, and increased vitality, social functioning and mental health -no difference in burden

Author (s), (Year) & Country	Study Design & Sample Characteristics	Intervention	Conceptual Framework & Outcome Measures	Findings
Hartke & King (2003). U.S.A.	-wait list RCT design -spouse caregivers of persons who had suffered a stroke; > 60 years -mean age 70 years -84 caregivers: 40 (tx group) & 44 (control group)	Type: telephone educational support group, mailed group manual Duration: 8 weekly sessions; 1 hour each Provider: Professionals, clinicians in area of psychology, social work or nursing	-stress & coping model -Depression (CES-D) -loneliness (UCLA Loneliness scale) -caregiver competence scale -Zarit Burden interview -Pressing Problem Index -Functional level (FIM) -baseline, time 2 (8 weeks) & time 3 (6 month follow-up)	-coherent measure of health developed (perceptions of health and self care) -majority of caregivers indicated good health, & handling stress -relationship found b/w injury & poor health -majority of findings not presented in this article
Mahoney, Tarlow & Jones (2003) U.S.A.	- RCT -investigated the main outcome effects of a interactive voice response (IVR) system -100 caregivers of persons with Alzheimer's Disease -49 in intervention group -51 in control group	Type: telephone linked care (TLC) is a computer mediated, interactive voice response system with voicemail to help family caregivers -telephone components: -counselling -in-home support grp -expert advice -respite conversation Duration: 12 months Provider: Clinical nurse specialist	-Yes – Pearlin framework (1990) -Revised Memory and Behaviour Problem Checklist (RMPBC) -State Anxiety Inventory -Depression scale (CES-D) -assessed at 6,12,18 months	- significant intervention effect for participants with lower mastery on all 3 outcomes - significant intervention effect for wives on RMBPC -no significant effect of intervention reducing problem behaviour, depression or anxiety

Author (s), (Year) & Country	Study Design & Sample Characteristics	Intervention	Conceptual Framework & Outcome Measures	Findings
Strawn & Hester (1998). U.S.A.	-before/after design -14 caregivers (of Alzheimer disease or dementia -purpose of study was to: 1)examine the utility of a telephone intervention (hotline- Telecare) 2)discuss any problems or emotions, serve as a source of social support, and provide info. if applicable	Type: contacts by a CC (Caring Caller) using a Conversational Symptom Assessment (CSA) -CC discuss caregiver's experiences, act as a source of social support, provide info: re: further supports Duration: weekly telephone contact x 12 weeks Provider: CCs were 9 graduate students in clinical psychology	- no framework cited -Brief Symptom Inventory -Zarit Burden Interview - assessments (2 pre-Telecare baseline times, mid/endpoint, 2 wks post Telecare	-Results indicate a reduction in overall stress & burden -caregivers highly valued Telecare -caregivers: increased self care & access of supports, grieved the loss of their loved ones, dealt with anger, and disclosed feelings

A 2: Descriptive Studies

Author (s), (Year) & Country	Study Design & Sample Characteristics	Intervention	Conceptual Framework & Outcome Measures	Findings
Coyne (1991). U.S.A.	-descriptive study - 257 callers to an information & referral telephone help-line specializing in dementia -96% Caucasian -78% were women; -mean age: 50.2 yrs; -72% were married; -125 (49%) return rate	Type: toll free helpline operated by the Comprehensive Services on Aging Institute for Alzheimer's Disease and Related Disorders -provides general info., & referral to community services, education and counselling Duration: N/A Provider: N/A	-No framework cited -25 item questionnaire developed to evaluate usage patterns -self-rated health -satisfaction with service	-Average of 4 requests for information & referral made per phone call -most common requests: home care services, info about dementia, adult day care, & support group -useful service in disseminating knowledge to caregivers

Author (s), (Year) & Country	Study Design & Sample Characteristics	Intervention	Conceptual Framework & Outcome Measures	Findings
Silverstein, Kennedy & McCormick (1993). U.S.A.	-descriptive study -assesses quality of help line of the Alzheimer's Association (eastern Massachusetts) -caregivers of persons with Alzheimer's who called the helpline - 36% of the callers were the primary caregivers -mean age: 45yrs -83% were female; -48% were employed full- time, -89% were Caucasian.	Type: hotline offering assistance & information Duration: N/A Provider: 13 graduate social work students; supervised by a psychologist	- no framework cited -the questionnaire was designed to obtain info. on satisfaction with the help line, caller demographics -extent of follow- through on information provided	-Overall satisfaction with the helpline was high, but callers who received follow-up information through the mail tended to report greater satisfaction -87% reported that they would call the helpline again -Reasons people called the helpline were more general than crisis oriented -Those individuals most likely to access the helpline were those with an inadequate support network
Skipwith(1994) U.S.A.	-descriptive study with case examples -caregivers of disabled elderly	Type: counselling at 3 levels, primary, secondary & tertiary; explored options providing health information, explored alternative resources, solving problems Duration: scheduled tri- weekly 15-minute telephone counseling sessions Provider: nurse	-no framework cited	-some concerns identified included lack of personal time, difficulty talking about feelings, poor health -telephone support helped caregivers problem solve, identify community resources

A-3 Qualitative Study:

Author (s), Year & Country	Study Design & Sample Characteristics	Intervention	Conceptual Framework & Outcome Measures	Findings
Stewart et al. (2001). Canada	-qualitative design -to test feasibility of a telephone support group intervention for persons with hemophilia & AIDS & their family caregivers -participants were 18+; with adequate functional status -caregiver group size = 4 + 2 facilitators	Type: telephone support groups -each session consisted of whatever topics the group members wanted to discuss Duration: 12 weeks ; approx. 105 mins Provider: sessions co-led by 1 professional facilitator, 1 peer facilitator	Yes- conceptual framework for support intervention	-telephone groups had support needs met -benefited from sharing info., -decreased feelings of isolation/ loneliness -caregivers thought it should be longer than 12 weeks

Appendix B: Methodological Rigor of Evaluation Studies

Author (s) & Year	Are Results Valid?	Results	Discussion & Limitations
Brown et al. (1999).	<ul style="list-style-type: none"> -quasi-experimental design -assignment of patients to groups not randomized (based on location of residence) -follow-up period: 2 years -no mention of blinding -interventions adequately described (telephone group & on-site group) -equal treatment in both groups -sufficient data describing participants -91 participants 	<ul style="list-style-type: none"> -outcome measures reliable & valid; focused on negative effects & family functioning -one scale was modified to fit the study -statistical significance in improvement in mood scores in both groups -low precision due to small sample size 	<ul style="list-style-type: none"> -limitations acknowledged in study (ie. small sample size; predominantly Caucasian sample; missing questionnaires) -all participants recruited from a brain injury rehabilitation program (non-generalizeable) -almost 30% drop-out rate (91/131) -some significant differences between 2 groups at baseline -respondent bias r/t missing questionnaires
Coyne. Potenza & Broken Nose (1995).	<ul style="list-style-type: none"> -RCT -limited description of the research design (ie. randomization procedure with no blinding evident) -limited description of questionnaire -groups did not differ at point of entry -baseline demographics described in adequate detail -sample: 51 completed questionnaires at both Times 1 & 2 	<ul style="list-style-type: none"> - only 52% return rate for questionnaires (bias related to low response rate) -outcome measures reliable & valid, but only acknowledged negative effects -low precision d/t small sample -increase in community supports statistically significant 	<ul style="list-style-type: none"> -limitations of study acknowledged (ie. low response rate) -bias r/t questionnaire -not generalizeable: callers were predominately white, middle aged, from urban New Jersey -caregivers reported severity of dementia diagnosis – not confirmed medically

Author (s) & Year	Are Results Valid?	Results	Discussion & Limitations
Davis (1998).	<ul style="list-style-type: none"> -before/after design (pilot study) -outcome assessor was blinded -adequate descriptions of research design -17 caregivers interviewed 	<ul style="list-style-type: none"> -low precision r/t small sample -outcome measures reliable, valid; acknowledged both negative and positive effects of caregiving -statistical significant increase of social support & life satisfaction; decrease in depression 	<ul style="list-style-type: none"> -limitations of study acknowledged (ie. small sample size; generalizability of sample - caregivers were recruited through a memory disorders clinic) -logs maintained by caregivers (potential source of bias) -demographics adequately described -bias r/t small sample size
Gitlin et al. (2003).	<ul style="list-style-type: none"> -multi-site RCT -interventions adequately described -randomization procedures described in great detail -1222 caregivers involved in study -6,12,18 month follow-up -assessors did not serve as interventionalists (to decrease bias) 	<ul style="list-style-type: none"> -increased precision d/t large sample size - only 2 outcome measurement tools used (both reliable & valid); & only assessed negative effects -only 1 result stat. significant (difference was small) 	<ul style="list-style-type: none"> -charts and graphs to supplement data -limitations acknowledged (unable to disaggregate which treatment elements are most important for decreasing burden; 6 month interval of data collection) -6 sites; sample comprised of Caucasian, Blacks & Hispanics (enhances generalizability) -only somewhat successful in achieving clinically meaningful outcomes -demographics described in adequate detail

Author (s) & Year	Are Results Valid?	Results	Discussion & Limitations
Goodman & Pynoos (1990).	<ul style="list-style-type: none"> -RCT -randomized comparison -baseline demographics described (groups similar at beginning of study) -66 caregivers -no blinding -12 week follow-up 	<ul style="list-style-type: none"> -decreased precision d/t small sample size -18.5% dropout rate -outcome measures reliable & valid; focused on negative outcomes & use of supports -results statistically significant (but little difference) 	<ul style="list-style-type: none"> -limitations of study were not acknowledged -results described in minimal detail -bias r/t small sample size
Grant et al. (2002).	<ul style="list-style-type: none"> -randomized, 3 group. repeated-measure control trial -assessors blinded to purpose of study (triple blinding) -inclusion criteria described in great detail -groups similar at start of study -18 month follow-up 	<ul style="list-style-type: none"> -74 stroke survivors & their caregivers (15% attrition & mortality rate) -outcome measures described in sufficient detail; reliable & valid -no statistical significance in burden -decreased precision d/t small sample 	<ul style="list-style-type: none"> -limitations acknowledged (ie. small sample size; limited focus on caregiving variables) -all participants recruited from 2 rehabilitation facilities: private & state, to enhance generalizability -demographics adequately described
Hartke & King (2003).	<ul style="list-style-type: none"> -wait list randomized control trial design -124/500 participants recruited (<25%) -88 persons remained until completion (30% drop-out rate) -6 month follow up 	<ul style="list-style-type: none"> -small sample (decreased precision) -measures reliable & valid; assessed negative effects, & caregiver competence -increase in competence 	<ul style="list-style-type: none"> -limitations acknowledged (ie. bias d/t restricted sampling procedures; intervention design too general) -demographics described

Author (s) & Year	Are Results Valid?	Results	Discussion & Limitations
Mahoney, Tarlow & Jones (2003)	<ul style="list-style-type: none"> - RCT (12 months) -randomization present -repeated measures approach for longitudinal data -100 caregivers involved in study -18 month follow-up -no mention of blinding 	<ul style="list-style-type: none"> -outcome measures reliable and valid; only negative effects measured -intention to treat analysis -stat. significant intervention effect for wives with low mastery 	<ul style="list-style-type: none"> -limitations of study were acknowledged a) sample not generalizeable - recruited from 3 sites near an academic medical centre; predominantly Caucasian and retired b) sample under enrolment & inadequate power for outcome analysis – possible Type 2 Error
Strawn & Hester (1998).	<ul style="list-style-type: none"> -before/after design -limited description of the research design - 14 caregivers -no randomization -no blinding 	<ul style="list-style-type: none"> -results minimally described in this article, but presented in another document -outcome measurement tools reliable & valid; focused on negative outcomes only -decreased precision d/t small sample 	<ul style="list-style-type: none"> -no mention of limitations of the study -unable to determine generalizeability of study d/t lack of detail re: sample -bias r/t small sample size

Appendix C: Methodological Rigor of Qualitative Study

Author (s) & Year	Are Results Valid?	Results	Discussion & Limitations
Stewart et al. (2001).	<ul style="list-style-type: none"> -qualitative design (pilot project) -use of conceptual framework to guide analysis -purpose/objectives of study described in sufficient detail -does not state type of qualitative design; sampling strategy 	<ul style="list-style-type: none"> -data collection and analysis described in sufficient detail -results indicate telephone support meets caregiver needs 	<ul style="list-style-type: none"> -ethical considerations mentioned (ie. informed consent & ethics approval) -limitation acknowledged (bias introduced during support group discussion through agenda setting and topic coverage) -interrater agreement included -no information re: investigator's perspectives

Appendix D:

GLOSSARY OF TERMS

Caregiving:	-providing care and/or assisting one with activities of daily living (ADLs) and instrumental activities of daily living (IADLs)
Informal Caregiver:	-a family member who has assumed responsibility for caring for a cognitively impaired person in the home
Provider:	-a professional who was and/or is affiliated with a community organization, and has provided telephone support to informal caregivers within the past year
Telephone Support:	-any type of support offered through a telephone conversation -may be provider or caregiver initiated
Formal Supports:	-services and programs provided through the Community Care Access Centre (CCAC) or similar centres (ie. VON, Seniors for Seniors, WeCare etc.), that offer professional assistance (visiting nurses, physiotherapists, occupational therapists, homemakers etc.)
Informal Supports:	-non-professional support provided by family, friends, peers from church or place of employment, neighbours etc.

Appendix : E

SCRIPT FOR EXECUTIVE DIRECTORS

[Information about the study]

1. Hello, it's _____ from the _____
(Alzheimer Society or the _____ Alzheimer Day Program).
2. I am calling you about a research study that is being done by a graduate student named Jenn Salfi at McMaster University.
3. The purpose of the study is to better understand the telephone support intervention, so that it can be determined whether or not this intervention is meeting the needs of caregivers of persons with dementia.
4. The study will involve two sources of information: (a) interviews with both caregivers and telephone support providers, and (b) contextual data including demographic details about all of the participants.
5. I am calling to see if you would be interested in participating in this study. Whether or not you agree to participate will not affect the services you are currently receiving from our organization.

[If the answer is no]

6. I respect your decision to not participate in the study. I thank you for your time, and I wish you the best in caring for your _____ (care receiver). Good-bye.

[If the answer is yes]

7. Do I have your permission to release your name and phone number to the researcher so that she may contact you?
8. The researcher will be contacting you in the next few weeks. At that time, you can decide whether you wish to continue to participate in the study, or decline the invitation to participate.
9. Do you have any questions?
10. I thank you for your time, and I wish you all the best in caring for your _____ (care receiver). Good-bye.

Appendix F: INITIAL TELEPHONE CONTACT WITH CAREGIVER

(All potential interviewees will have been contacted by the Executive Directors of the agency and informed of the project prior to receiving this telephone call/consent.)

[Information about the study]

1. Hello, my name is Jenn Salfi and I am a graduate student at McMaster University. I am conducting a study that explores the experiences of telephone support. I will be looking at two sources of information. I plan to collect contextual data from the participants and agencies involved, and interview both telephone support providers and caregivers.
2. ___(Executive Director)___ from the _(agency)___ gave me your name because you are a family caregiver who has recently received telephone support. I understand that you are presently caring for _____(husband, wife, mother, father...)
3. Would you be interested in sharing some of your experiences with me in a face-to-face interview?

[If the answer is no]

4. May I ask why not?
5. I respect your decision to not participate in this study. I thank you for your time, and I wish you the best in caring for your _____(care receiver). Good-bye.

[If the answer is yes]

6. Thank you. I do appreciate your willingness to participate. We can meet at your home, or any other place that is convenient for you. Interviews may last anywhere from 30-60 minutes.

[Confidentiality]

7. Whatever you tell me during the interview will be confidential. This means that only people you tell about the interview will know what you've said. I will not share what you have told me with the telephone support agency or provider. If you decide to share information with your telephone support provider about what was said in your interview that will be your decision.

8. I will be taking notes during the interviews, and if it is o.k. with you, I would also like to tape record the interviews to make sure that I do not miss any important information.
9. All information is anonymous. This means that any names on the tapes or other materials associated with the project will be removed or concealed. Information that you provide will be combined with information from other people and used to describe groups of caregivers, not just an individual caregiver.
10. All tapes and written documents will be stored in a locked filing cabinet. Only myself and the three members of my research committee will have access to the information. Do you have any questions so far?

[Voluntary participation, risks, benefits]

11. Taking part in this project is voluntary. This means that we can't begin to ask you any questions until you agree to participate in this study. Even after you agree to be in this project, you can withdraw at any time and for any reason, or refuse to answer any question. Your decision on whether or not to participate in this study will not affect any services you receive or seek now or in the future.
12. Although there are no known risks associated with this study, some people may feel some discomfort when discussing aspects of care and the caregiving experience. If this happens, you can stop the interview. You have the right to reschedule the interview if you wish. I will also provide you with a list of local resources that may help ease any discomfort you may feel.
13. There are no known direct benefits for anyone taking part in this project. The information that you give to me, however is important as it will raise awareness of the strengths and weaknesses of telephone support, so that improvements can be made to this type of service in the future.

[Verifying informed consent]

14. Do you have any questions about the information I have just given you?

[If respondent has questions, provide information as needed]

15. Are you still interested in participating in an interview session?

[If no, ask what changed the person's decision.]

[If yes, continue with the following conversation]

[Preparation for the interview]

16. Thank you for choosing to participate in this study. You will be receiving a package in the mail within the next week. In the package will be 2 items: a brief description of the study, and 2 copies of the consent forms outlining what I have discussed with you during this phone call.
17. If you understand all of the items on the consent form and feel comfortable with what it tells you, you can sign and date both copies of the form. If you have any questions, please wait until I arrive and we can discuss them before we begin the interview.
18. Now, we need to set a date and time that is convenient for both of us. I am available 0900-1700 Mondays and Tuesdays. What days and time are generally good for you?

[Set a date and time for the interview. Ask for directions to respondents home.]

19. Thank you very much for your time and willingness to participate in the study. I look forward to our meeting on (day/date/time). Take care. Good-bye.

Signature of Research Participant

I understand the information provided for the study "Seeking to Understand Telephone Support" as described herein. My questions have been answered to my satisfaction, and I agree to participate in this project. I will receive a signed copy of this form.

Caregiver/Provider Name:

Printed

Signature

Date

Signature of Investigator

In my judgement, the participant is voluntarily and knowingly giving informed consent and possesses the legal capacity to give informed consent to participate in this research study.

Investigator:

Printed

Signature

Date

Appendix J :

DEMOGRAPHIC DATA

Caregiver

Age:

Gender:

Relationship to Care Receiver:

Living Arrangement:

Employment Status:

Duration of Caregiving:

Number of Other Caregivers:

Health:

Care Receiver

Age and Gender of Care Receiver:

Diagnosis of Care Receiver:

Severity of Cognitive Impairment:

Other impairments:

Appendix K : CONTACT SUMMARY FORM

Contact Type:
Visit _____
Phone _____

Site:
Contact Date:
Today's Date:
Written By:

1. What were the main issues or themes that struck you in this contact?

2. Summarize the information you received (or failed to receive) on each of the target questions you had for this contact.

Question

Information

3. Did anything else strike you as salient, interesting, illuminating, or important in this contact?

Appendix L: INTERVIEW GUIDE FOR CAREGIVERS

[Introduction]

1. You've signed the consent form, which means that you understand the goals of the study and the interview process. Remember, you have the right to end the interview at any time, not answer certain questions, or reschedule the interview if you feel uneasy or uncomfortable at any point. Are you ready to begin?

[The Caregiving Experience:
Negative & Positive Consequences; Coping Mechanisms]

2. The first group of questions I will ask you relate to your experiences of caregiving.

- A. What has it been like for you to be the main caregiver for [care receiver] ?
- B. What have you enjoyed the most about caring for [care receiver]?
- C. What has been most difficult for you in caring for [care receiver]?
- D. How has caregiving affected your life?
- E. What strategies have you used to help you cope with caregiving? Did this work (or is this working) for you? Describe.
- F. Are you receiving any help (formal or informal) with caregiving? Who? Did this work (or is this working) for you? Describe.
- G. Would you change anything in your experience as a caregiver?
- H. Is there anything else you would like to tell me about?

[Telephone Support]:

3. Thank you for sharing your experiences with me. Now I'd like to ask you some questions about the telephone support that you received, and about your opinions on this particular service for assisting caregivers at home, such as yourself.

- A. Describe the telephone support that you have received in the past year.
(Probe: information support, emotional support, referral).
- B. From your personal situation, what were some of the strengths of telephone support?
- C. What were some of the limitations of telephone support?
- D. Is there anything that you would like to change about the telephone support that you have received? Describe. (For example: amount, type, provider, availability).
- E. Would you recommend telephone support to other caregivers? Why or why not?

- F. In your opinion, has telephone support assisted you in caring for your loved one? Describe.

[Thank you].

4. Thank you, for your time and valuable contribution to my project. If you have any questions about the interviews or the status of this study, feel free to contact me. You have my phone number and email address.

- Do not read items in bold out loud.

Appendix M: INTERVIEW GUIDE FOR PROVIDERS

[Introduction]

1. You've signed the consent form, which means that you understand the goals of the study and the interview process. Remember, you have the right to terminate the interview at any time, not answer certain questions, or reschedule the interview if you feel uneasy or uncomfortable at any point. Are you ready to begin?

[Telephone Support]:

2. I'd like to ask you some questions about telephone support in general, and about your opinions on this particular service for assisting caregivers at home.

- A. Describe the telephone support that you are most likely to give (Probe: explaining the disease/behaviors; referring to community services; validating emotions/concerns; listening).
- B. What do you believe are some of the strengths of telephone support, as a service for caregivers at home?
- C. What are some of the limitations of telephone support?
- D. Is there anything that you would suggest changing about the telephone support service that you provide? Describe. (For example: hours of availability; topics of discussion).
- E. Would you recommend telephone support to caregivers? Why or why not?
- F. How would you describe the impact of telephone support on caregivers of persons with dementia?

3. The next set of questions I will be asking you pertain to your experiences while providing telephone support. Would you like to continue?

[Experience with Telephone Support]

- A. How long have you been providing telephone support to caregivers in the community? What is your background?
- B. What have you enjoyed the most about providing telephone support? Describe a memorable experience.
- C. What has been most difficult for you while providing this type of support?
- D. What strategies do you use or have you used to help you cope with these difficult situations?
- E. Do you receive any type of support (formal or informal) as a telephone support provider? Who? Did this work (or is this working) for you? Describe.

- F. Would you change anything in your experiences as a telephone support provider?
- G. Is there anything else you would like to tell me about?

[Thank you].

4. Thank you, for your time and valuable contribution to my project. If you have any questions about the interviews or the status of this study, feel free to contact me. You have my phone number and email address.

- Do not read items in bold out loud.

Appendix N: CRITIQUE CHECKLIST FOR A CASE STUDY REPORT (Stake, 1995).

1. Is the report easy to read?
2. Does it fit together, each sentence contributing to the whole?
3. Does the report have a conceptual structure (ie. themes or issues?)
4. Are its issues developed in a serious and scholarly way?
5. Is the case adequately defined?
6. Is there a sense of story to the presentation?
7. Is the reader provided with some vicarious experience?
8. Have quotations been used effectively?
9. Are headings, figures, artifacts, appendices, and indexes used effectively?
10. Was it edited well, then again with a last minute polish?
11. Has the writer made sound assertions, neither over or under interpreting?
12. Has adequate attention been paid to various contexts?
13. Were sufficient raw data presented?
14. Were data sources well chosen and in sufficient number?
15. Do observations and interpretations appear to have been triangulated?
16. Is the role and point of view of the researcher nicely apparent?
17. Is the nature of the intended audience nicely apparent?
18. Is empathy shown for all sides?
19. Are personal intentions examined?